

PDF hosted at the Radboud Repository of the Radboud University Nijmegen

The following full text is a publisher's version.

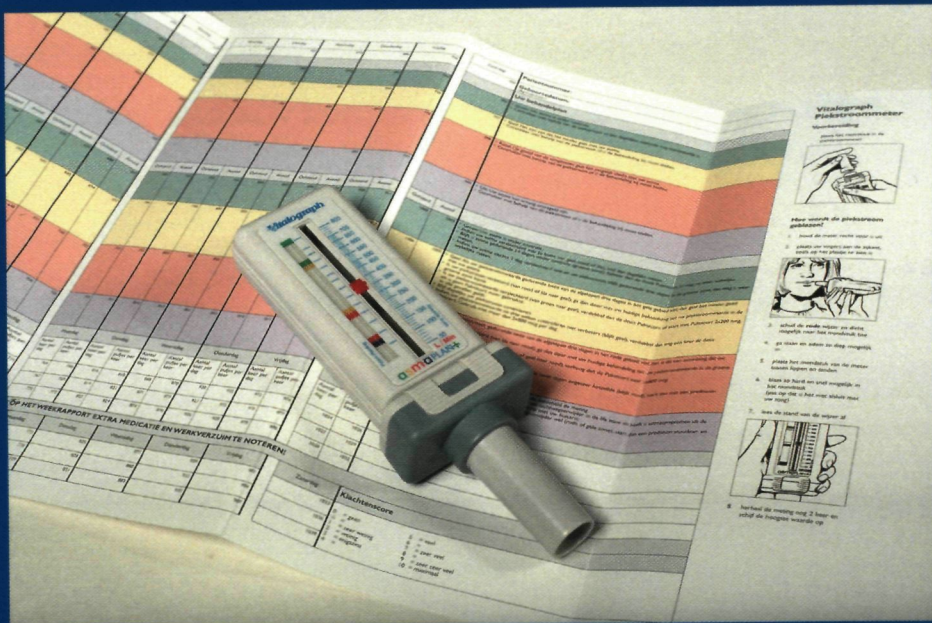
For additional information about this publication click this link.

<http://hdl.handle.net/2066/144562>

Please be advised that this information was generated on 2018-07-07 and may be subject to change.

Selfmanagement of asthma in General Practice

B.P.A. Thoonen



Self-management of asthma in General Practice

The study presented in this thesis was performed at the Department of General Practice/Family Medicine of the University Medical Centre Nijmegen, which participates in the Netherlands School of Primary Care Research (CaRe), which is acknowledged by the Royal Dutch Academy of Science (KNAW)

The study presented in this thesis was financed by grants from the Netherlands Organisation for Scientific Research (NWO 904-58-091 and NWO904-68-486) and by a research grant from AstraZeneca BV.

Production of this thesis was kindly sponsored by:

AstraZeneca BV

Novartis Pharma BV

Boehringer Ingelheim and Pfizer

Lay out: T Jeijnsman

Printing: Ponsen & Looijen BV

© BPA Thoonen

ISBN: 90-5073-006-x

Arnhem / Nijmegen 2002

Self-management of asthma in General Practice

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

Proefschrift

Ter verkrijging van de graad van doctor aan de
Katholieke Universiteit Nijmegen
op gezag van de Rector Magnificus Prof.dr. C.W.P.M. Blom,
volgens besluit van het College van Decanen
in het openbaar te verdedigen
op woensdag 16 oktober 2002
des namiddags om 1.30 uur precies
door
BPA Thoonen
geboren op 29 augustus 1965
te Oss

Promotores:

Prof dr CP van Schayck, Universiteit van Maastricht

Prof dr R Grol

Copromotor:

Dr G van den Boom

Manuscriptcommissie:

Prof dr CLA van Herwaarden

Prof dr A Verbeek

Prof dr T van der Molen, Universiteit Groningen / University of Aberdeen

**Voor mijn (schoon-)ouders,
die dit mogelijk hebben gemaakt**

Contents

Chapter 1: Introduction	9
Chapter 2: Present and future management of asthma and COPD: proceedings from WONCA 1998.	21
Chapter 3: Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view.	31
Chapter 4: Willingness of patients to perform self-management of asthma and the role of inhaled steroids.	45
Chapter 5: Asthma education tailored to individual patient needs can optimise partnerships in asthma self-management	57
Chapter 6: Self management of asthma in general practice, asthma control and quality of life: a randomized controlled trial	73
Chapter 7: A randomised-controlled economic evaluation of asthma self-management in primary health care	95
Chapter 8: Self management in asthma care.	129
Chapter 9: Role of family physicians in implementing asthma self-management programs	133
Chapter 10: General discussion	149
Chapter 11: Summary (in Dutch) - Samenvatting	161
Appendix I: GP manual for patient education: general instructions and example of first visit (both in Dutch)	175
Dankwoord	183
Curriculum vitae	189
Publicaties	191

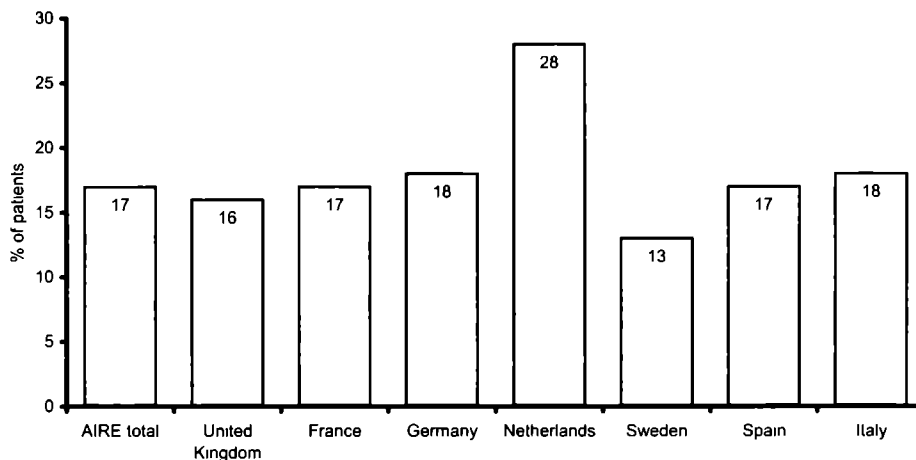
Chapter 1

Introduction

Background

Asthma is a chronic inflammatory pulmonary disease with a significant socio-economic impact on patients and their family¹. The understanding that airway inflammation is the key underlying process has led to the early introduction of inhaled corticosteroids in guidelines for the management of asthma²⁻⁵. Following these developments, asthma management in the Netherlands has shifted from exacerbation-management to disease management in the last 2 decades. There is a high acceptance rate of inhaled corticosteroids and a reduction in emergency room visits, hospitalisations and unscheduled GP-visits can be observed. Although standards are high in this perspective, Smeele et al demonstrated that prior to the start of our ZBA-study presented in this thesis, there still was a substantial group of asthma and COPD patients who did not reach the target level of control as stated in the 1992 asthma/COPD guidelines^{6;7}. The overall impact on (socio-economic) burden of disease is still substantial, as is illustrated in figure 1.1. It demonstrates that 28% of Dutch asthma patients over 16 years of age has had lost work or school days in the past year due to asthma^{8;9}. Moreover, this percentage is the highest of all participating European countries. As is described in chapter 2 of this thesis several strategies have been advised and developed to improve outcomes of asthma management, but non-compliance could become one of the major factors limiting the effectiveness of new and old treatments. Poor compliance with prescribed inhaled therapy is an important cause of uncontrolled disease^{10;11-14} which in turn is associated with an impaired quality of life^{15,16} and is presumably responsible for three quarters of the total costs of asthma¹ in the US. Based on differences in the delivery of care, cost of uncontrolled disease can be expected to be relatively lower in the Netherlands. However, Smeele et al found that more than 20% of all patients with asthma or COPD continuously used their bronchodilator for more than twice daily and 25% had at least one exacerbation in the last three months⁷, indicating that there is room for improvement. Improving compliance in terms of stressing the continuous use of maintenance therapy may not be the most efficient solution. Based on current insights it is unclear how long maintenance therapy needs to be continued. Additionally there are indications that inhaled steroids can be tapered off

Figure 1.1: Percentage of patients that has lost work/school days in the past year due to asthma



or stopped during a certain period or at least reduced to the minimal effective daily dose that provides adequate control of the disease(17;18). Optimising treatment for the individual patient may balance benefits and risks and leads to a more efficient and cost effective treatment. Such treatment optimisation can be achieved through self-management. In this thesis self-management of asthma is interpreted as a broad concept involving aspects of patients taking control of their own disease(19). This includes autonomous decision-making, self-monitoring and the use of a written self-treatment plan(20). Such written self-treatment plan instructs patients to vary their dosage and frequency of inhaled steroids, based on self-assessed peak-flow values and asthma symptoms.

Aim of the ZBA-study was to study to what extent self-management based on patient education, skills training and a written self-treatment plan results in more efficient and cost effective treatment.

Components of self management

Written self-treatment plan

Instructions in the self-treatment plan are based on the patients' self assessed asthma conditions. Such self-monitoring gives patients the opportunity of guidance on decisions they make regarding their asthma-treatment and feedback on the effects of these decisions. There are two major sources of feedback available for self-monitoring: peak flow values and asthma symptoms.

Peak flow measurements can easily be performed by patients and may indicate airway narrowing²¹⁻²⁶. When related to the personal best value this parameter can provide information on both deteriorating and well-controlled asthma. Ideally daily peak-flow measurements should provide the most detailed information about asthma control. When well-controlled however superfluous information is gathered and patients make unnecessary efforts. We therefore advised weekly peak-flow measurements. In the presence of alarm symptoms or a drop of peak flow values below 80 percent of the personal best value, patients were instructed to change to daily measurement of peak flow values and symptoms.

Based on self assessed changes in peak flow values patients were advised to stepwise stop, halve or double their dosage of inhaled steroids. Patients also received instructions on when to start a course of oral steroids (30mg prednisolone per day, during 1 week). Cut-off points for peak-flow were 80, 60 and 40% of a patients' personal best value²⁰. To reduce the number of erroneous decisions a 'decision-delay' was introduced when asthma control possibly deteriorated. Asthma treatment had to be intensified only if peak-flow values were reduced during at least two out of three consecutive days²³. Self-management instructions are summarised in detail in Box 1.1 and the self-treatment diary is shown in Figure 1.2.

Symptoms were added as an extra indicator of asthma control. Onset of deteriorations of asthma control is notorious for a great variety in symptoms and peak-flow changes. Symptoms can precede changes in peak-flow on the one side of the spectrum, whereas drops in peak-flow without any noticeable symptoms are on the other side of the spectrum. When both symptoms and peak-flow are regularly assessed, they can act as back-up systems for each other. When asthma is well

Box 1.1: Detail of the self treatment plan

Step-up instructions

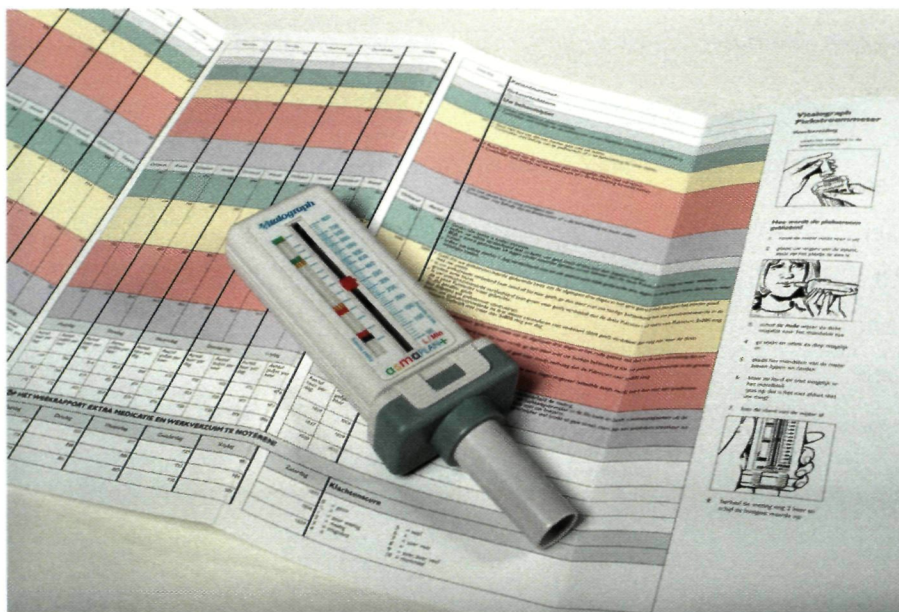
- *Peak flow deteriorates $<80\%$ PEFR $\geq 60\%$ of Personal Best Value (PBV) for 2 out of 3 consecutive days:*
 - double budesonide dosage
 - in case of insufficient response within three weeks: again double budesonide dosage
- *Peak flow deteriorates $<60\%$ PEFR $\geq 40\%$ of PBV for 2 out of 3 consecutive days:*
 - increase budesonide dosage to 800 micrograms b.i.d.
 - in case of insufficient response within two days: start course of oral prednisolone
 - and contact your FP
- *Peak flow deteriorates $<40\%$ of PBV:*
 - If sufficient response to bronchodilator: start course of oral prednisolone
 - Else: immediately contact your GP

Step-down instructions

- *Peak flow improves to $\geq 40\%$ PEFR $<60\%$ of PBV:*
 - continue the current budesonide dosage until your PEFR is $>80\%$ of PBV
- *Peak flow improves to $\geq 60\%$ PEFR $<80\%$ PBV:*
 - continue the current budesonide dosage until your PEFR is $>80\%$ of PBV
- *Peak flow improves to $\geq 80\%$ of PBV:*
 - halve budesonide dosage when PEFR $\geq 80\%$ for a period of six weeks

controlled patients are advised to measure their peak-flow once every week in order to detect deteriorations without symptoms. When asthma symptoms occur between weekly peak-flow measurements, the self-treatment plan gives the advice to initiate daily peak-flow measurements to verify if a true deterioration of asthma-control is at hand. It is currently believed that waking at night due to asthma and increased use of bronchodilator are the most sensitive symptoms of deterioration⁵. We used these symptoms as the first indicators of decreased asthma control.

Figure 1.2: Self-treatment diary card



Patient education and skills training

Self-management has the objective to empower patients with the knowledge and skills to treat their own illness. The self-management program studied in this thesis was constructed around the concept of shared responsibilities²⁰. It aims at patients shifting from reliance on their physician as the one telling them what to do, towards feeling more responsible for ones own choices and willingness to explore ones own possibilities. The GP has a responsibility for optimising the circumstances under which patients can make decisions and in supporting patients in successfully

changing their behaviour. Aim of patient education and skills training is to provide the asthma patient with information and tools needed for successful performance of the self-treatment plan. However, there may be a discrepancy between what the patient wants to know on the basis of own interests or previous knowledge and what the patient needs to know according to the health professional. As an effort to bridge this possible gap between the patients' and the health professionals' agenda patients were given a tool to indicate to the GP what they wanted to know themselves about their asthma (feedback) and thus influenced the contents of their own asthma education. Because of the increased involvement of the patient in his or her own education this approach was called tailored education. Specific skills that were trained within this tailored education program were inhalation technique and peak-flow measurement.

This thesis

In chapter 2 self-management of asthma in general practice is positioned and identified as an area needing additional research. In 1998 basic principles of self-management were discussed on the WONCA world-conference. The self-management program studied in this thesis is based on those principles: patient education, skills training and a written self-treatment plan. Educating and training patients as described above requires changes in the role of GP and patient. Before introducing our program in general practice we first explored if patients and general practitioners were interested in such treatment strategy. In chapter 3 acceptance of self-management by GPs is studied by comparing expectations of Dutch GPs with knowledge and experience of British GPs. In chapter 4 acceptance of self-management by patients is studied. It was hypothesised that asthmatics have a high interest in the possibility of reducing their personal dosage of inhaled steroids. But subjects using higher doses of inhaled steroids may be more reluctant as dose reduction may lead to unwanted loss of asthma control²⁷. Chapter 4 studies the role of the dosage of inhaled steroids in the acceptance of self-management by patients. In chapter 5 we studied whether our self-management program succeeded in incorporating the patients' needs and if this resulted in higher patient satisfaction.

In chapter 6 effects on asthma control, quality of life and lost-activity days are studied.

Chapter 7 explores costs and savings induced by the program and their relation with successfully treated weeks, quality of life and quality adjusted life years.

During the course of the ZBA study several other authors have studied effects and benefits of self-management. Combined with experiences from our own ZBA-study our own and other insights progressed. In chapters 8 and 9 the role and position of self-management is discussed based on these proceeding insights and they are the preamble to chapter 10 in which the actual conclusions and recommendations of the ZBA-study are discussed.

References

1. Barnes PJ, Jonsson B, Klim JB. The costs of asthma. *Eur Respir J* 1996; 9(4):636-642.
2. Bone RC. Goals of asthma management. A step-care approach [see comments]. *Chest* 1996; 109(4):1056-1065.
3. British Thoracic Society. Guidelines on the management of asthma. *Thorax* 1993; 48(Supplement):S1-S24
4. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997; 52(Supplement 1):S1-S21.
5. anonymous. Global strategy for asthma management and prevention
NHLBI/WHO workshop report 95-3659. 1995. National heart, lung and blood institute
6. van der Waart MAC, Dekker FW, Nijhoff S, Thiadens HA, van Weel C, Helder M et al. NHG-standaard CARA bij volwassenen: behandeling [NHG Guideline on CNSLD in adults: treatment]. *Huisarts Wet* 1992; 35(11):437-443.
7. Smeele IJM, Grol RPTM, van den Bosch WJ, van Schayck CP, Haverkort AFM, Molema J. Knelpunten in de zorg voor volwassen CARA-patienten [Quality of care for adult patients with asthma/COPD in general practice]. *Huisarts Wet* 1996; 39(12):548-53.
8. GlaxoWellcome. AIRE: Asthma Insights and Reality in Europe. 1999. Middlesex UK, Respiratory Therapeutic Development.
9. Rabe KF, Vermeire PA, Soriano JB, Maier WC. Clinical management of asthma in 1999: the Asthma Insights and Reality in Europe (AIRE) study. *Eur Resp J* 2000; 16:802-807.
10. Cochrane GM. Compliance and outcomes in patients with asthma. *DRUGS* 1996; 52 Supplement:12-19.
11. Bosley CM, Parry DT, Cochrane GM. Patient compliance with inhaled medication: does combining beta- agonists with corticosteroids improve compliance? [see comments]. *Eur Respir J* 1994; 7:504-509.
12. Yeung M, O'Connor SA, Parry DT, Cochrane GM. Compliance with prescribed drug therapy in asthma. *Respir Med* 1994; 88(1):31-35.

13. Dompeling E, van Grunsven PM, van Schayck CP, Folgering H, Molema J, van Weel C. Treatment with inhaled steroids in asthma and chronic bronchitis: long-term compliance and inhaler technique. *Fam Pract* 1992; 9:161-166.
14. Horn CR, Clark TJ, Cochrane GM. Compliance with inhaled therapy and morbidity from asthma. *Respir Med* 1990; 84:67-70.
15. Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health related quality of life in asthma: development of a questionnaire for use in clinical trials. *Thorax* 1992; 47:76-83.
16. Juniper EF, Guyatt GH, Ferrie PJ, Griffith LE. Measuring quality of life in asthma. *Am Rev Respir Dis* 1993; 147:832-838.
17. van Grunsven PM, Dompeling E, van Schayck CP, Molema J, Folgering H, van Weel C. Treatment of mild asthma with inhaled corticosteroids: Is discontinuation of therapy possible? *Fam Med* 1996; 28:46-51.
18. van Schayck CP. Periodic treatment regimens with inhaled steroids in asthma or chronic obstructive pulmonary disease Is it possible? *JAMA* 1995; 274(2):161-164
19. Neville R. Patient education and guided self-management plans. *Resp Med* 1996; 90:385-386
20. Partridge MR. Delivering optimal care to the person with asthma: what are the key components and what do we mean by patient education? *Eur Respir J* 1995; 8:298-305.
21. Malo JL, L'Archeveque J, Trudeau C, d'Aquino C, Cartier A. Should we monitor peak expiratory flow rates or record symptoms with a simple diary in the management of asthma? [see comments] *J Allergy Clin Immunol* 1993; 91(3):702-709.
22. Drummond N, Abdalla M, Beattie JAG, Buckingham JK, Lindsay T, Osman LM et al. Effectiveness of routine self monitoring of peak flow in patients with asthma. *BMJ* 1994; 308:564-567.
23. Gibson PG, Wlodarczyk J, Hensley MJ, Murree-Allen K, Olson LG, Saltos N. Using quality-control analysis of peak expiratory flow recordings to guide therapy for asthma. *Ann Intern Med* 1995; 123(7):488-492.
24. Reddel HK, Salome CM, Peat JK, Woolcock AJ. Which index of peak expiratory flow is most useful in the management of stable asthma? *Am J Respir Crit Care Med* 1995; 151:1320-1325.
25. Jackson AC. Accuracy, reproducibility, and variability of portable peak flowmeters. *Chest* 1995; 107:648-651.

26. Boezen HM, Schouten JP, Postma DS, Rijcken B. Relation between respiratory symptoms, pulmonary function and peak flow variability in adults. *Thorax* 1995; 50:121-126.
27. Haahtela T, Jarvinnen M, Kava T, Kiviranta K, Koskinen S, Lehtonen K et al. Effects of reducing or discontinuing inhaled budesonide in patients with mild asthma. *New Engl J Med* 1994; 331(11):700-705.

Chapter 2

Present and future management of asthma and COPD: proceedings from WONCA 1998.

BPA Thoonen¹, CP van Schayck¹, C van Weel¹, ML Levy², R Spelman³, D Price⁴, D Ryan⁵, D Bellamy⁶, P van Grunsven¹, S Cloosterman¹, G van den Boom¹, W Gorgels¹, H Schönberger⁷

¹ Dept. of General Practice and Social Medicine, Nijmegen University, The Netherlands

² The Kenton Bridge Medical Centre, Kenton Middlesex, UK

³ Bridgetown Health Centre, Bridgetown Killinick, Ireland

⁴ School of Health, Policy and Practice, University of East Anglia, Norwich, UK

⁵ Woodbrook Medical Centre, Loughborough, Leicestershire, UK

⁶ James Fisher Medical Centre, Bournemouth, UK

⁷ Dept of General Practice, University of Maastricht, The Netherlands

Published in: Family Practice; 1999;3:312-15

Abstract

On 15 June 1998, a workshop on asthma and chronic obstructive pulmonary disease (COPD) was held at the WONCA conference in Dublin. Based on the current guidelines for diagnosis and treatment of asthma and COPD, new developments and present and future research projects were discussed. Based on these guidelines and the research findings, new developments were positioned. The final conclusion of this workshop was that there is a need to continue exchanging ideas at an international level. So an initiative to start a Scientific Group of Primary Care Research within the European Respiratory Society has been taken.

Introduction

On 15 June 1998, a workshop on asthma and chronic obstructive pulmonary disease (COPD) was held at the WONCA conference in Dublin. The aim of the workshop was to discuss present and future developments in the fields of asthma and COPD in general practice. This workshop was a joint venture of the British and Irish GPs in asthma groups (GPIAG) and the Asthma/COPD in General Practice Research Group of the University of Nijmegen, the Netherlands.

Recent advances in asthma

An increasing number of guidelines on the diagnosis and treatment of asthma and COPD exists^{1;3-8}. Before applying one of those guidelines, an accurate diagnosis is essential. Based on data from the DIMCA study⁹, CP van Schayck (University of Nijmegen/Maastricht, The Netherlands) showed that much asthma and COPD still remain undiagnosed (20-60%), and that the prevalence of these diseases is increasing despite improved treatment. The DIMCA study also shows that undiagnosed patients respond positively to inhaled steroids and could be treated and diagnosed as asthmatics. As there are as yet no validated primary preventive measures, the importance of improving early diagnosis was emphasised. Detection of undiagnosed asthma patients is a major challenge for the future. The DIMCA study showed that screening the annual decline in forced expiratory volume in one second (FEV₁) in subjects with chronic cough and shortness of breath may be an effective

strategy for tracing undiagnosed asthma or COPD. Whether this approach is cost-effective has yet to be established.

M Levy (GPIAG, UK) discussed several methods in use to administer inhaled medication for acute asthma. He concluded that spacers may be useful in general practice, but scientific evidence is lacking, as present studies investigating the usefulness of spacers are not yet applicable for general practice. Another option discussed by M Levy was the usefulness of pulse-oximetry to monitor the patient during the treatment of an acute asthma attack. Pulse-oximetry, combined with an oxygen-driven nebulizer, may be an efficient way to treat acute asthma attacks and prevent sudden, life-threatening hypoxaemias.

The role of long-acting beta-2 agonists was reviewed by D Ryan (GPIAG, UK). Prior to their clinical use, fears had been expressed¹⁰ about the regular use of beta-2 agonists, as this appeared to destabilize asthma. Two randomized controlled trials in mild to moderate¹¹ and moderate to severe¹² asthma demonstrated their efficacy when compared to doubling up the dose of inhaled steroids. The measures where superiority was observed were improved morning and evening peak flow measurements, reduction in rescue use of short-acting beta-2 agonists, and reduction in morning and evening symptom scores. An increase in asthma exacerbations was not observed in the group using salmeterol.

A further study¹³ using a double-blind crossover design demonstrated that when patients used a long-acting beta-2 agonist in conjunction with a strict self-management plan, a reduction of inhaled steroid dose of 17% could be achieved. Finally, a year-long study¹⁴ examined the effects of adding an inhaled beta-2 agonist to both lower and higher doses of inhaled steroids in patients with persisting symptoms over a period of 1 year. It found that the addition of long-acting beta-2 agonists improved both symptoms and pulmonary function without any increase in exacerbation rate. In summary, long-acting beta-2 agonists are a useful and effective adjunct to treatment in patients whose asthma is not controlled under low-dose inhaled corticosteroids.

Currently, exact positioning for the Leukotriene Antagonist is not entirely clear, but current evidence was reviewed by Dr D Price (GPIAG, UK) along with a suggested positioning. Leukotriene antagonists clearly improve all clinical end-points in asthma,

including FEV₁, independent of beta agonists and, at least to some extent, inhaled steroids. This would suggest that leukotriene pathways have not been fully treated by our more traditional asthma therapies. It was recommended that they may be useful for patients failing to respond fully to inhaled steroids and beta-agonist therapy. When prescribing leukotriene antagonists, a trial of between 1 week and 1 month should verify whether patients respond to this class of therapy.

At the end of this session, P van Grunsven (University of Nijmegen, The Netherlands) presented data from the DIMCA study on aspects of compliance. The success of any treatment depends on the compliance of patients. Compliance for anti-inflammatory treatment was approximately 70% of the prescribed dose during the study period and no predictors for compliance could be identified^{15,16}. Most frequently, self-reported reasons for non-compliance were the absence of symptoms, experiencing (or fearing) side-effects and not having the time to take the medication. If treatment of early asthma and early COPD is shown to be effective, then non-compliance to inhaled steroids may be a major obstacle. Therefore, compliance should regularly be assessed during follow-up visits. Repeat education may be an important tool to enhance compliance.

Management of asthma and COPD

The second session focused on the actual usage of the present guidelines. The BTS issued their revised guidelines on the management of asthma¹ and COPD⁸ in 1997; one of the changes was the advice to use self-management programmes. Scientific evidence of the beneficial effects of these programmes is building up, but questions remain on what plans to use and which patient may profit from them most. B Thoonen (University of Nijmegen, The Netherlands) demonstrated that self-management plans revolve around the increased sharing of responsibilities between GP and patient, and introduced the concept of self-managed education. Self-managed education keeps interests of both GP and patient in mind, and thus decreases the specific information needs of patients. As this approach to self-management of asthma is still under examination, further results will probably follow in the near future.

R Spelman (GPIAG, Ireland) discussed the usage of current guidelines by the GPs. He showed that almost 50% of Irish GPs use asthma guidelines, often locally adjusted national guidelines. As these local guidelines take into account the accessibility of local resources and prescribed medication, they are often a more pragmatic translation of the common guidelines. On the basis of the NHBLI/Gina guidelines², Spelman demonstrated that choosing the proper treatment for patients is not always a matter of gradually stepping up. First, a thorough severity assessment should be done, and subsequently treatment is started on the appropriate severity step. Starting with higher doses (step down regimen) may reduce the overall cumulative dosage of (inhaled) steroids, while this may add to the risk of overtreating some patients during certain periods.

C van Weel (University of Nijmegen, The Netherlands) demonstrated that most of the statements in various asthma guidelines are also applicable to children. However, there are some major differences. One of the specific actions for asthmatic children is the monitoring of growth and development. This provides both information of the severity of asthma and of possible growth inhibition due to prescribed (anti-inflammatory) medication. There are specific difficulties when diagnosing asthma in children. In contrast with adults, it often takes an observation period of up to three years to diagnose childhood asthma. During these 3 years it is difficult to give proper advice. Even when asthma is diagnosed, there are some specific therapeutic aspects which differ from the adult guidelines. In order to avoid side-effects of anti-inflammatory treatment, it may be best to prescribe a trial of therapy based on symptoms. During the process of diagnosing and treating asthma, it is also important to pay attention to the family situation. Barriers to effective treatment may very well be not only at the level of the patients but at the level of the parents as well. D Bellamy (GPIAG, UK) discussed the present BTS COPD guidelines which were recently published in Thorax⁷. COPD is a very common disease that causes considerable morbidity, poor quality of life and 26 000 deaths per year in the UK. The diagnosis and management of COPD still is a neglected area, with many primary care physicians merely telling patients to stop smoking and suggesting that nothing else can be done for them. Smoking is certainly the most important cause of COPD, and smoking cessation offers the most effective means of preventing disease

progression. However, only 20% of the smokers develop COPD, and at present the co-factors that make this group susceptible have not been identified. The guidelines propose a more holistic view of treatment. Therapeutic options include bronchodilators (the cornerstone of symptomatic improvement in breathlessness, wheeze and exercise), corticosteroids, rehabilitation training, long-term oxygen and surgery. It is also important to address social problems and treat the secondary depression that often accompanies severe COPD. Immunization against influenza may help to prevent infective exacerbations. According to the BTS guidelines, goals of the management of COPD are: early and accurate diagnosis of COPD, optimising symptom control, preventing deterioration of lung function and complications, and improving the quality of life. The use of spirometry by GPs is strongly encouraged to diagnose and assess the severity of COPD. Patients with moderate or severe COPD should undergo a steroid reversibility study to determine whether inhaled steroids will be beneficial in long-term management. Long-acting bronchodilators improve symptoms and the quality of life, but more studies are needed to fully evaluate their use.

Asthma and COPD research in primary care

In the third and final session, results from recent research projects and some upcoming projects were presented.

S Cloosterman (University of Nijmegen, The Netherlands) discussed two recent placebo-controlled studies on the effects of house dust-mite avoidance measures on asthma symptoms, FEV₁ and peak flow in allergic patients with and without asthma¹⁷. She concluded that house-dust-mite-impermeable mattress covers were capable of reducing the amount of house dust-mite allergen. These reductions were followed by improvements in morning peak flow and symptom scores in patients with no diagnosed asthma. In patients with asthma, bronchial hyperresponsiveness and FEV₁ did not change significantly. Allergic patients without asthma showed an earlier and greater response than allergic patients with asthma. Therefore, house dust-mite avoidance measures seem to be more useful and effective in early stages of asthma^{18;19}. The underlying mechanism of this phenomenon is still unclear and requires further research.

The PREVASK study, a new research project to assess whether early prenatally started interventions may lead to preventive effects on the development of asthma in infants was presented by H Schönberger (University of Maastricht, The Netherlands). He presented data from general practice which suggest a genetic predisposition for developing asthma. Many of the relevant risk factors are often already known to the GP and are easily recordable. Exposure to these risk factors may lead to the expression of genetic predispositions and might well be preventable. In the PREVASK study, the effects of reduction of exposure will be evaluated the next few years.

G van den Boom (University of Nijmegen, The Netherlands) presented a cost-effectiveness study based on the DIMCA project²⁰. Screening of subjects from the open population during a maximum of 12 months traced approximately 20% of the open population with undiagnosed asthma or COPD. The costs per detected case were US\$ 564, which is relatively little compared with other screening programmes. Treatment was initiated for these patients and the effects and costs will be evaluated in the near future in a cost-benefit analysis. Screening of a population followed by treatment of newly diagnosed patients will always incur extra expense. It is important to weigh up these costs against the gains in health and quality of life - a so-called cost-effectiveness study - to support medical decisions and health policies. One of the recent developments in the treatment of COPD patients is treatment with *N*-acetylcysteine as an anti-oxidant drug. The effectiveness of this therapy on relevant parameters such as decline in FEV₁, exacerbation rates and quality of life is still unknown. W Gorgels (University of Nijmegen, The Netherlands) demonstrated the supposed anti-oxidant effects of *N*-acetylcysteine and the design of the recently started COOPT study. This 3-year study compares the efficacy of *N*-acetylcysteine and fluticasone dipropionate in a placebo-controlled design among 600 COPD patients recruited from at least 30 general practices.

The final speaker of this workshop was M Levy, who presented the effects of training practice nurses in an asthma training centre. Training practice nurses improved the organisation of asthma management and increased confidence in patients in the advices given. Practices with trained nurses used self management plans more frequently. One of the negative effects, however, was that compliance to follow up visits was dramatically reduced. Although the data presented came from a relatively

small study, the results did show relevant changes in the organization and management of asthma in general practice, so M Levy concluded that the effects of training nurses on practice management needed further addressing.

Conclusion

This international initiative to make an inventory of present and future developments in the management of asthma and COPD was of great value. There proved to be a clear consensus on the place of some new developments in the treatment of asthma and COPD in general practice, such as the use of long-acting bronchodilators and leucotriene antagonists. It was concluded that priorities of research in these fields are the detection of unknown patients, further placement of non-steroid anti-inflammatory treatment and the effects of self-management. As all guidelines promote the usage of spirometry, further research on the implementation of this technique in general practice needs to be promoted.

Although relevant differences in the various national guidelines are present, comparison of these guidelines showed that there is an increasing convergence in ideas about how chronic airway diseases should be treated. Asthma and COPD have a high prevalence in general practice, and the majority of patients are treated by the GP. Therefore, it is important that current guidelines also take into account general-practice-based evidence. The present and future research projects presented in this workshop clearly showed that research in general practice can and will provide this scientific evidence. In order to prevent redundancy, it is important that these research efforts are well co-ordinated at an international level. The final conclusion of this workshop therefore was that there is a need to continue exchanging ideas at an international level. The WONCA conference offers a good opportunity for this purpose. Another possibility is to form a Scientific Group of Primary Care Research within the European Respiratory Society, as this also provides an easy interface between primary and secondary respiratory care. An initiative to start such a Scientific Group has been taken already, and we would welcome any national group of GPs or individuals to join this initiative.

References

1. British Thoracic Society. Guidelines on the management of asthma. *Thorax* 1993;48(Suppl):S1-S24.
2. National Heart L, and Blood Institute. International consensus report on diagnosis and treatment of asthma. *Eur Respir J* 1992;5:601-41.
3. Geijer RMM, Thiadens HA, Smeele IJM, van der Zwan AAC, Sachs APE, Bottema BJAM, van Hensbergen W, van Schayck CP, van Weel C, Rosmalen CFH. NHG-Standaard COPD en astma bij volwassenen: diagnostiek. *Huisarts Wet* 1997;40(9):416-29.
4. Geijer RMM, van Hensbergen W, Bottema BJAM, van Schayck CP, Sachs APE, Smeele IJM, Thiadens HA, van Weel C, van der Zwan AAC, Rosmalen CFH. NHG-Standaard astma bij volwassenen: behandeling. *Huisarts Wet* 1997;40(9):443-54.
5. Geijer RMM, van Schayck CP, van Weel C, Sachs APE, van der Zwan AAC, Bottema BJAM, Smeele IJM, Thiadens HA, van Hensbergen W, Rosmalen CFH. NHG-Standaard COPD: behandeling. *Huisarts Wet* 1997;40(9):430-42.
6. Siafakas NM, Vermeire P, Pride NB, Paoletti P, Gibson J, Howard P, Yernault JC, Decramer M, Higenbottam T, Postma DS, et al. Optimal assessment and management of chronic obstructive pulmonary disease (COPD). The European Respiratory Society Task Force [see comments]. *Eur Respir J* 1995;8(8):1398-420.
7. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997;52(Supplement 1):S1-S21.
8. The COPD Guidelines Group of the Standards of Care Committee of the BTS. BTS Guidelines for the management of chronic obstructive pulmonary disease. *Thorax* 1998;52 Suppl 5:S1-S28.
9. van den Boom G, Rutten-van Molken MPMH, Tirimanna PRS, van Schayck CP, Folgering HTM, van Weel C. Association between health-related quality of life and consultation for respiratory symptoms: results from the DIMCA programme. *Eur Respir J* 1998;11:67-72.
10. Sears M, Taylor D, Lake D, Li Q, Flannery E. Regular inhaled B-agonist treatment in bronchial asthma. *Lancet* 1990;336:1391-1396.
11. Greening A, Ind P, Northfield M, Shaw G. Added salmeterol versus higher-dose corticosteroid in asthma patients with symptoms on existing inhaled steroid. *Lancet* 1994;344:219-224.

12. Woolcock A, Lundback B, Ringdal N, Jacques L. Comparison of addition of salmeterol to inhaled steroids with doubling of the dose of inhaled steroids. *Am J Respir Crit Care Med* 1996;153:1481-1488.
13. Wilding P, Clark C, Coon JT, et al. Effect of long-term treatment with salmeterol on asthma control: a double blind, randomised crossover study. *Br Med J* 1997;314:1441-1446.
14. Pauwels R, Lofdahl C, Postma D, et al. Effect of inhaled formoterol and budesonide on exacerbations of asthma. *New Engl J Med* 1997;337:1405-1411.
15. van Grunsven PM, van Schayck CP, Molema J, Akkermans RP, van Weel C. Treatment of preclinical asthma or chronic obstructive pulmonary disease (COPD) with inhaled steroids in the 'DIMCA' project (an early detection, monitoring and intervention program in asthma and COPD): acceptable compliance rates. *Am J Resp Crit Care Med* 1997;155(4part2):A309.
16. van Grunsven PM, van Schayck CP, van Deuveren M, van Herwaarden CLA, Akkermans RP, van Weel C. Compliance during long-term treatment with fluticasone propionate in subjects with early signs of asthma or chronic obstructive pulmonary disease (COPD): Results of detection, intervention and monitoring program of COPD and asthma (DIMCA). *J Asthma* 2000;37:225-234.
17. Cloosterman SGM, Hofland ID, Lukassen HGM et al. House dust mite avoidance measures improve peak flow and symptoms in patients with allergy but without asthma: A possible delay in the manifestation of clinical asthma? *J Allergy Clin Immunol* 1997;100:313-319.
18. Custovic A, Simpson A, Chapman MD, Woodcock A. Allergen avoidance in the treatment of asthma and atopic disorders. *Thorax* 1998;53:63-72.
19. Platts-Mills TAE, Vervloet D, Thomas WR, Aalberse RC, Chapman MD. Indoor allergens and asthma: report of the third international workshop. *J Allergy Clin Immunol* 1997;100:1S-24S.
20. van den Boom G, van Schayck CP, Rutten-van Molken MPMH, et al. Active detection of chronic obstructive pulmonary disease and asthma in the general population. Results and economic consequences of the DIMCA program. *Am J Respir Crit Care Med* 1998;158:1730-1738.

Chapter 3

Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view.

BPA Thoonen ¹, K P Jones ², HA van Rooij ¹, AC van den Hout ³, I Smeele ⁴, R Grol ⁴, CP van Schayck ¹

¹ Dept. of General Practice and Social Medicine, Nijmegen University

² Dept of Primary Health Care, Newcastle University

³ Dept of Public Affairs, Nijmegen University

⁴ Interuniversity Quality of Care Group, Nijmegen University

Published in: Family Practice;1999;2:117-22

Abstract

Objectives: Self-management of asthma is becoming more and more widespread. The implementation of this treatment strategy requires changes in the role and attitude of the GP. These changes may be hindered by obstacles both expected and experienced. As self-treatment of asthma is more common in the UK, comparison between UK and Dutch GPs provides a good opportunity to identify possible obstacles in general practice to the implementation of self-treatment of asthma with inhaled corticosteroids.

Methods: We carried out a qualitative descriptive study with self-administered questionnaires and interviews. Questionnaires were sent to 500 randomly selected Dutch GPs. Interviews were held with 20 Dutch and 25 British GPs in order to acquire more in-depth information. The outcome measures were attitude towards, knowledge regarding and experiences with self-treatment of asthma; organizational requirements; and expectations of consequences of self-treatment in general practice.

Results: The Dutch and British GPs investigated have a positive attitude towards self-treatment of asthma. Though knowledge about self-treatment is present among a majority of the GPs, self-treatment by patients is not yet as common in The Netherlands as it is in the UK. Nineteen per cent of the Dutch GPs had experience with a written peak-flow-based self-treatment plan related to the usage of inhaled steroids. According to our findings, present expected obstacles are probably mainly of organizational kind, such as the availability of time, money and materials.

Conclusions: There is a positive attitude towards the implementation of self-treatment plans in general practice, problems relating to certain identified obstacles need to be addressed. There is a need to define which patients might profit from self-treatment, and further proof of both the clinical effectiveness and the cost-effectiveness of self-treatment needs to be acquired.

Background

In the last decade, interest in self-treatment of asthma has increased and several studies with different self-treatment strategies have been published. After the first positive results of a self management plan in the United Kingdom, published by

Beasley *et al.* in 1989¹, others also found clues that self-management and self-treatment programmes may lead to improvement of patients' outcomes^{2 6}. Some researchers, however, found more moderate results or even little or no evidence for beneficial effects of self-treatment programmes^{7 9}. Most of the positive research has been done among out-patient populations and attenders at accident and emergency departments, so results may be not applicable to general practice. Furthermore, as there are great differences between designs, outcome parameters and contents of the self-management programmes used, it is difficult to compare the results, but at least components such as patient education and peak-flow assessments are felt to have some proven value^{3,4,10}.

Guidelines for asthma treatment in the UK and the US have emphasized the use of self-management plans^{11 13}, but guidelines for general practice in The Netherlands have not thus far advised the use of such plans on a broader scale¹⁴. The use of self-treatment plans among Dutch GPs is therefore less common. Implementation of effective self-treatment plans in general practice might require a change in the role and attitude of the GP. Instead of 'prescripctor' the GP becomes educator and coach.

Objectives

Self-management of asthma seems to be an effective way of managing asthma, and present evidence may justify a change in treatment strategy. Before implementing this change in treatment, the obstacles to this change should be identified¹⁵. The purpose of this paper is to assess if GPs are willing to make these changes and what obstacles they might encounter during these changes. As self-treatment of asthma is already more common in the UK, comparison between UK and Dutch GPs provides a good opportunity to assess the obstacles encountered and expected when implementing self-treatment in general practice. The following questions were explored:

- What is the present knowledge of self-treatment of asthma among Dutch GPs?
- How do Dutch GPs use self-treatment plans at present?
- What are the attitudes of Dutch GPs towards the implementation of asthma self-treatment?

- Do Dutch GPs have realistic expectations about the implementation of self-treatment plans in comparison with their more experienced UK colleagues?
- What are the experienced obstacles and problems regarding the implementation of asthma self-treatment in general practice in the UK and in The Netherlands?

Methods

In the literature there are several definitions for self-treatment and self-management. In this study we used the following definition: self-treatment of asthma means that patients vary their dosage and frequency of inhaled steroids based on peak-flow values and/or asthma symptoms, as described in a written plan. We consider this form of self-treatment to be a component of the broader concept of asthma self-management¹⁶.

This study was conducted in two phases: first, questionnaires were sent to 500 randomly selected Dutch GPs. The questionnaires provided information from a large group of GPs. However, as they contained mainly closed questions, they were not the most suitable instrument for gaining proper insight into the opinions of the GPs. So, secondly, 20 Dutch GPs and 25 British GPs were interviewed in a standardized way.

Questionnaire phase

A random selection of 500 GPs across all of The Netherlands received a questionnaire. After 1 month a reminder was sent to non-responders. GPs were asked to report reasons for not responding to the questionnaire on a separate form, in order to investigate a possible recruitment bias. As no previous instrument was suitable, a structured, closed-end-question (multiple choice), 20-item questionnaire for postal distribution and self-completion was designed specifically for this study. Face validity was examined by discussion with clinical colleagues. The following GP characteristics were studied: age; type of practice: solo, duo, group, health centre, else; urbanization: >30 000 inhabitants, <30 000 inhabitants, rural; and membership of Dutch College of General Practitioners. In relation to research questions 1 and 2, we asked for familiarity with self-treatment plans (yes, no, a little; symptom-based versus peak-flow-based; with inhaled bronchodilators and/or with inhaled steroids).

Information about attitudes and expectations was provided by the following items: possible advantages and disadvantages of self-treatment plans; reasons for not applying self-treatment plans; attitude towards self-treatment plans (useful, because...; not useful, because...); willingness to implement self-treatment plans (eager to, probably want to, don't know yet, probably not, not); reported possible obstacles. Data were analysed using the SAS 6.07 under CMS statistical package.

Interview phase

Twenty of the Dutch GPs who returned the questionnaires were also interviewed in their practices. As it is obviously that familiarity with self-treatment of asthma is needed in order to have an opinion about it, these 20 GPs were randomly selected from among those GPs who mentioned being familiar with the concept of self-treatment of asthma. Additionally, 25 GPs in the Tyneside area of North-East England, selected as broadly in favour of proactive asthma care by one of the authors (KJ), were interviewed about their attitudes and experiences with self-treatment of asthma. The interviews with the Dutch and British GPs utilized a standard set of questions. The contents of the interview are summarised in table 3.1.

Table 3.1: Contents of the interviews

Concept of self-management of asthma

personal definition; commonness of self-management; enthusiasm about self-management; advantages and disadvantages

Experiences with self-management:

years of experience; number of patients with self-management; organisational obstacles; necessary equipment.

Attitude towards self-management:

is self-management a meaningful alternative for patients and for the GP; motives to start using self-management; willingness and capability of patients to perform self-management.

Organisational conditions

how was self-management introduced; received instructions prior to introduction; time investment for GP and practice nurse; consequences for the number of consultations, prescribed medication, financial resources, available time and the role of the practice nurse

Results

As the interviews were designed to obtain more elaborate information about the same subjects who completed the questionnaire, results are presented simultaneously. Where relevant, the source of the information will be specified. The overall response rate to the questionnaire was 59%. Of the 500 questionnaires originally sent out, 287 (57%) were suitable for further analysis. Six forms were not completed at all, and 207 forms were not returned. Of these 207 non-responders, 47 GPs in total gave 63 reasons for not responding. The most common reason for not responding was lack of time (90% these 47, see table 3.2).

Table 3.2: Reported reasons for not responding to the questionnaire (more than one reason possible; 47 GPs, 63 answers)

Reason given	No. Of GPs	%
Lack of time	42	90
No experience with self-treatment	9	20
Not willing to co-operate	5	10
Personal reasons	5	10
Disagreement with design	2	5

Table 3.3 shows some of the characteristics of the GPs who returned the questionnaire. When comparing the type of practice characteristics with figures from the Dutch Institute for Primary Care Research (NIVEL), the sample should in this extent be representative of all Dutch GPs²⁸. One hundred and three (36%) GPs reported to be very (well) familiar with the concept of asthma self-treatment, 141 (49%) were somewhat familiar with it, and 43 (15%) had never heard of this self-treatment concept. 'No experience with self-treatment' was reported by 20% of the non-responders as a reason for not responding. Presuming that the group of non-responders with no experience with self-treatment is comparable with the responders that had never heard of this self-treatment concept (15%), there might have been some recruitment bias. One hundred and fifty-three (65% of GPs with some kind of experience, 53% of total responders) of the GPs had experience with self-treatment with inhaled steroids, based on asthma symptoms, whereas 45 (19% of GPs with

some kind of experience, 16% of total responders) had experience with peak-flow-based programmes.

Table 3.3: Characteristics of participating GPs (questionnaire)

Age	Years		
Mean	45		
Range	32-64		
Type of practice	No.	%	NIVEL (%)
Solo	136	48	53
Duo	90	32	29
Group	31	11	9,4
Health centre	26	9	8,6
Urbanisation	No.	%	
Rural	79	28	
Small town (<30 000 inhabitants)	62	22	
Urban (>30 000 inhabitants)	146	50	

Advantages

In both the questionnaire and the interview, Dutch GPs reported several possible advantages of self-treatment in various areas: for patients, prescribing, health costs and GPs. Reported advantages for patients were an increase in self-efficacy, higher patient satisfaction and greater independence and responsibility. Self-treatment programmes could lead to a better control of the disease as a consequence of earlier recognition of symptoms and less doctor-induced delay in treatment. Patients might suffer fewer and milder exacerbations; furthermore, as a consequence of better control, the long-term effects of asthma might be reduced. More efficient medication usage may lead to fewer side effects and perhaps better compliance. From an economic point of view, fewer medical consultations in both primary and secondary care may be needed, together with less use of additional medications. Although GPs expect that the implementation of self-treatment plans initially will take up more of

their time, in the long term, as a result of better asthma control, self-treatment might lead to a reduction in emergency visits and intercurrent visits to the GP and thus save time.

Disadvantages

The Dutch GPs felt that as self-treatment requires specific knowledge, skills and patient awareness, this approach is only possible for a selected group of patients. These requirements may well result in extra GP workload for the teaching of self-treatment programmes to patients. Also a lower contact frequency could lead to less medical control of the disease. Misinterpretation of symptoms and wrong treatment decisions by patients could lead to an increased delay in seeking medical help and a consequent more rapid decline in lung function. The long-term influence of self-treatment on the course of asthma is still unknown. At the medication level, self-treatment programmes could result in overtreatment or undertreatment and decreased compliance. In economic terms, more complications may well lead to an increased need for treatment and medical resources, with an attendant rise in health care costs. In the interviews with British GPs most of the GPs explained that they had not (yet) encountered any of these negative effects.

Willingness to implement self-treatment plans

Sixty-eight GPs (24% of total responders) did not promote self-treatment of asthma with inhaled steroids for one or more reasons. Their stated reasons for not applying self-treatment are summarized in table 3.4. Most of the GPs reported that they had never really thought about the implementation of self-treatment, or did not know how to start with the implementation of self-treatment plans. Among the GPs who reported self-treatment with inhaled steroids to be useful (164, 57%), almost 90% of the GPs were more or less willing to start self-treatment (see table 3.5). This is 51% of the total numbers of responders.

Reported obstacles

Of the above 164 GPs, 41 (25%) thought that there would be no consequences for daily practice in commencing asthma self-treatment, but reported expected obstacles

Table 3.4: Reasons for not applying self-treatment with inhaled steroids

(n=68, 24% of total responders; more than one reason possible)

Reason	No.	%
Never thought about using self-treatment	26	38
Difficult to make a start	17	25
I do not (don't) know how to apply self-treatment	14	21
No benefit for the patient	7	10
Not enough time	4	6
Other reasons	11	16

Table 3.5: Willingness of GPs to start with self-treatment of asthma

(if thought to be useful; n=164)

	No.	%
Eager to start	71	43
Probably wants to start	75	46
Doesn't know yet	10	6
Will probably not start	7	4
Will definitely not start	1	1

by the remainder were: availability of time, availability of necessary materials (peak-flow devices, diary cards, etc), delegation of tasks and the role of the practice assistant or nurses, and changes needed in the role of the GP. During the interviews with the British GPs some experienced obstacles were reported that need to be taken into account when implementing self-treatment of asthma in general practice. These obstacles were mainly of a practical nature. Necessary materials (e.g. peak-flow devices, diary cards) need to be available. At the start of the implementation of self-treatment, an extra time investment is needed. Later on, as reported by the GPs, this time investment will be paid back, because of a decreasing number of emergency visits and consultations. Tasks need to be clearly divided among the GP and the practice nurse, and both need to use the same protocol of care. The lack of such a

clearly described protocol was reported as one of the obstacles. Setting up a so-called asthma clinic was reported as a good solution to overcome most of the organizational problems.

We also studied the relationship between knowledge of self-treatment of asthma, age, type of practice, earlier experiences with self-management of diabetics and the willingness to start implementing self-treatment. The only relationship we found was a positive association between the familiarity of the GP with the concept of self-treatment of asthma and his/her willingness to start implementing such self-treatment (see table 3.6).

Table 3.6: Relation between knowledge of and willingness to start with self-treatment.

	Eager to start	May start	Don't know if	Probably not start	Not start
Knows self-treatment very well	40	15	1	1	1
Has heard of self-treatment	31	59	8	6	0
Has never heard of self-treatment	0	1	1	0	0

Discussion

Our results indicate that 57% of the Dutch GPs in our sample have a positive attitude towards the implementation of asthma self-treatment plans in general practice. Many have at least some knowledge about this innovation in care, but experience with the use of self-treatment is more limited. When comparing the expected disadvantages of the Dutch GPs with the experienced disadvantages of the British GPs, Dutch GPs may overestimate the possible disadvantages of self-treatment of asthma. On the other hand they do have a realistic understanding of the potential obstacles in primary care which need to be overcome in the more widespread promulgation of self-treatment, and their views in this area are echoed by the experiences of the UK GPs interviewed.

The increasing prevalence of asthma, among other factors, has also led to an increased burden of asthma morbidity¹⁷⁻²⁰. Since the majority of asthma management for both acute and chronic episodes occurs in general practice^{21;22}, it is important that the community care of this common disease is optimized. The publication of numerous consensus-based guidelines on asthma management over the last decade has been a welcome advance^{11;12}, as has been the more recent production of evidence-based documents²³. Proof of the effectiveness of such guidelines has gradually appeared, but there has often been insufficient focus on the organizational aspects of asthma care outside hospitals.

The development of asthma self-management plans has to some extent mirrored that of guidelines. Some original hospital-based experience indicated that they may be beneficial¹, and their use, particularly in the UK, then became widespread.

Further community-based research has followed quite slowly, but some at least of the literature now indicates benefits for patients^{2,5;24}.

Some important lessons have emerged from earlier experiences. First, showing beneficial outcomes of such care has proven to be difficult, and present-day research findings are not all in favour of self-management. Secondly, it is still unclear which patients might profit most from self-management programmes, but there are indications that these plans do not necessarily apply to all patients. For example, self-treatment based on peak-flow meters is not suitable for all patients and symptom-based self-treatment programmes are, under certain circumstances, equally effective as peak-flow-based programs^{7;25}.

If the potential advantages of asthma self-treatment are to be realized in the community, there is a need for clear guidelines, describing how to implement self-treatment of asthma in general practice and defining the patients that might profit from self-treatment. Current differences in available self-treatment plans need to be regularized²⁶. In the interviews with the British GPs, the need for a clear division of tasks and a useful protocol of care was expressed. Organizational requirements are likely therefore to play crucial roles in delivering optimal asthma care. A recent UK publication by Neville *et al.* underlines the possible influence of practice organization and audit on clinical outcome measures in general practice asthma care²⁷.

Clearly, interest in self-treatment programmes among Dutch GPs is increasing. Knowledge and attitude towards self-treatment of asthma do not seem to be obstacles for the implementation of self-treatment programmes. However, training practice assistants or practice nurses and GPs, and reorganizing general practice in order to implement a self-treatment programme take time and money. Resources of potential benefit to patients with asthma could be wasted if strict attention to training of practice assistants or nurses and the production of efficient protocols is not given.

As a consequence of this study, a self-treatment programme tailored to Dutch general practice will be developed and further research to assess the clinical and cost-effectiveness of this self-treatment programme initiated.

References

1. Beasley R, Cusley M, Holgate ST. A self management plan in the treatment of adult asthma. *Thorax* 1989;44:200-4.
2. Lahdensuo A, Haahtela T, Herrala J, et al. Randomised comparison of guided self management and traditional treatment of asthma over one year. *BMJ* 1996;312:748-52.
3. Taitel MS, Kotses H, Bernstein IL, Bernstein DI, Creer TL. A self-management program for adult asthma. Part II: Cost-benefit analysis. *J Allergy Clin Immunol* 1995;95:672-6.
4. Kotses H, Bernstein IL, Bernstein DI, et al. A self-management program for adult asthma. Part I: Development and evaluation. *J Allergy Clin Immunol* 1995;95:529-40.
5. Ignacio Garcia JM, Gonzalez Santos P. Asthma self-management education program by home monitoring of peak expiratory flow. *Am J Respir Crit Care Med* 1995;151:353-9.
6. D'Souza W, Crane J, Burgess C, et al. Community-based asthma care: trial of a "credit card" asthma self-management plan. *Eur Respir J* 1994;7:1260-5.
7. Jones KP, Mullee MA, Middleton M, Chapman E, Holgate ST. Peak flow based asthma self-management: a randomised controlled study in general practice. British Thoracic Society Research Committee. *Thorax* 1995;50:851-7.
8. Bernard Bonnin AC, Stachenko S, Bonin D, Charette C, Rousseau E. Self-management teaching programs and morbidity of pediatric asthma: a meta-analysis. *J Allergy Clin Immunol* 1995;95:34-41.
9. Drummond N, Abdalla M, Beattie JAG, et al. Effectiveness of routine self monitoring of peak flow in patients with asthma. *BMJ* 1994;308:564-7.
10. Partridge MR. Delivering optimal care to the person with asthma: what are the key components and what do we mean by patient education? *Eur Respir J* 1995;8:298-305.
11. British Thoracic Society. Guidelines on the management of asthma. *Thorax* 1993;48(Supplement):S1-S24.
12. Expert Panel on the management of asthma. Executive Summary: guidelines for the diagnosis and management of asthma. *J Allergy Clin Immunol* 1991;88(3pt2):425-534.
13. The British Thoracic Society et al. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997; 52: (Suppl 1).

14. Geijer RMM, Van Hensbergen W, Bottema BJAM, et al. NHG-standaard astma bij volwassenen: behandeling. Huisarts Wet 1997;40(9):443-54
15. Grol R. Beliefs and evidence in changing clinical practice. BMJ 1997;315:418-21.
16. Neville R. Patient education and guided self-management plans. Resp Med 1996;90:385-6.
17. Jones KP. Asthma care in general practice -time for revolution? British Journal of General Practice 1991;41:224-5.
18. Gellert AR, Gellert SL, Iliffe SR. Prevalence and management of asthma in a London inner city general practice. British Journal of General Practice 1990;40:197-201.
19. Bauman A, Mitchell CA, Henry RL, et al. Asthma morbidity in Australia: an epidemiological study. Med J Aust 1992;156:827-31.
20. Roberts SJ, Bateman DN. Which patients are prescribed inhaled anti-asthma drugs? Thorax 1994;49:1090-5.
21. Charlton IH, Bain DJG. The care of children with asthma in general practice: signs of progress? Br J Gen Pract 1991; 41: 256.
22. Neville RG, Clark RC, Hoskins G, et al, for the General Practitioners in Asthma Group. National asthma attack audit 1991-2 Br Med J 1992;306: 559-562.
23. North of England Asthma Guideline Development Group. North of England Evidence Based Guidelines Development Project: evidence based guidelines for the primary care management of asthma in adults. BMJ 1996; 312: 762-6.
24. Kotses H, Stout C, McConnaughy K, Winder JA, Creer TL. Evaluation of individualized asthma self-management programs. J Asthma 1996;33(2):113-8.
25. Charlton I, Charlton G, Broomfield J, Mullee MA. Evaluation of peak flow and symptoms only self management plans for control of asthma in general practice. BMJ 1990;301:1355-9.
26. Meijer RJ, Kerstjens HAM, Postma DS. Comparison of guidelines and self-management plans in asthma. Eur Resp J 1997; 10: 1163-1172.
27. Neville RG, Hoskins G, Smith B, Clark RA. Observations on the structure, process and clinical outcomes of asthma care in general practice. British Journal of General Practice 1996;46:583-7.
28. NIVEL. Jaarboek Nederlands Instituut voor Eerstelijnsgezondheidszorg, Utrecht, 1993.

Chapter 4

Willingness of patients to perform self-management of asthma and the role of inhaled steroids.

Bart PA Thoonen¹, Tjard RJ Schermer¹, Reinier P Akkermans¹, Joost J den Otter¹, Richard Grol² and Onno CP van Schayck^{1,3}.

¹ Department of General Practice, University Medical Centre St Radboud, Nijmegen, The Netherlands,

² Centre for Quality of Care Research, University Medical Centre St Radboud, Nijmegen and Maastricht, The Netherlands,

³ Department of General Practice, University of Maastricht, The Netherlands

Published in: Scan J of Prim Health Care 2002;20:60-4

Abstract

Objective: Asthma self-management is a generally accepted effective treatment strategy for asthma patients. Acceptance by patients may be a barrier for successful implementation. In this study, the role of inhaled steroids in starting asthma self-management is described.

Design: Cross-sectional explorative study.

Setting: General Practice.

Subjects: 283 adult steroid-requiring asthma patients were invited by their GP to participate in a self-management programme.

Main outcome measures: In a multivariate logistic regression model, the relation between baseline dosage of inhaled steroids, occupational status, age and sex as independent variables and willingness to participate as dependent variables was explored.

Results: Of all invited, 148 (52%) were willing to participate. Subjects not using inhaled steroids were least willing to participate (43/143 = 30%). Subjects with low doses of inhaled steroids (<400 mcg daily) were most willing to participate (44/54 = 81%). Unemployed asthmatics had a higher tendency to participate than patients with a regular job.

Conclusion: Acceptance of self-management by patients is not a limiting issue in promoting self-management of asthma in general practice. High acceptance in patients taking low or intermediate doses of inhaled steroids makes general practice the most appropriate setting for self-management. A selection procedure is recommended.

Introduction

A key component of asthma guidelines is educating the patient. The finding that education should not be administered without an action plan, self-monitoring and regular review¹ has led to the introduction of self-management programmes. Several randomised controlled trials have demonstrated that self-management of asthma is beneficial from both the perspective of both GPs and the patients^{2;3}.

When implementing self-management, there are certain barriers (time investment, division of tasks, materials) that may be encountered by GPs, and setting up an asthma clinic can be a good solution in overcoming these problems⁴. To make this implementation process more efficacious, identification of all patients who may profit from self-management and selection of those willing to participate in such treatment strategy are the first steps.

One of the key components of asthma self-management is tapering off inhaled steroids. Fear and dislike of inhaled steroids are described as playing a role in compliance^{5;6}. It is likely that asthmatics have a high interest in the possibility of reducing their personal dosage of inhaled steroids. On the other hand, subjects using higher doses of inhaled steroids may be more reluctant as dose reduction may lead to unwanted loss of asthma control⁷. This paper studies the role of the dosage of inhaled steroids in the introduction of self-management in general practice. Based on findings from a pilot study we included age and sex in this study too⁸.

During the initial recruitment we observed that lack of time due to work was one of the most frequent reasons for non-participation. Employment or study thus may be a barrier for patients to participate so this factor was included as well.

Patients and methods

In this cross-sectional explorative study, 23 GPs first identified all asthma patients requiring inhaled steroids aged between 16 and 60 years from their practice population. The information sources used were problem list codings (based on the International Classification of Primary Care), prescription data from practice records and the local pharmacist and annual influenza vaccination campaign lists. All selected patients were invited to participate in a self-management programme consisting of three initial education and training visits, regular (weekly or daily) self-assessment of symptoms and peak flow and adjustment of inhaled steroids according to their self-assessed asthma condition. Patients could indicate their willingness to participate by returning an enclosed form to the investigators. Patients who did not return the form were classified as not willing to participate. For patients who refused to participate, or did not respond to the invitation, the following data were provided anonymously by the subject's GP: age, sex, dosage of inhaled steroids and occupational status.

Patients willing to participate were invited to a lung function laboratory where they were checked for in- and exclusion criteria, as defined in table 4.1 and data on age, sex, dosage of inhaled steroids and occupational status were collected.

Table 4.1: In- and exclusion criteria

Inclusion criteria:

Treated for asthma by the GP
and age between 16 and 60 years
and FEV₁ more than 40% of the predicted value and more than 55% of predicted 15 min after inhalation of 800 µg salbutamol or 6 weeks after inhalation of 800 µg budesonide twice daily
and reversibility FEV₁ (after bronchodilation with 800 µg salbutamol MDI or 8 weeks treatment with 800 µg budesonide twice daily) of at least 10% of the predicted value
or PC₂₀ histamine ≤ 8 mg/ml

Exclusion criteria:

- Smoking history of 15 or more pack years
 - Serious other diseases than asthma with a low survival rate
 - The patient has had exacerbations during a period of 1 month before the start of the study
 - Other diseases which influence bronchial symptoms and/or lung function (e.g. decompensatio cordis, sarcoidosis)
 - The patient is unable to inhale medication correctly or to measure and record their peakflow adequately and it is unlikely that this can be taught.
-

Analysis

The dependent variable in this study was willingness to participate (yes/no). Independent variables were 'usage of inhaled steroids', 'occupational status', age and sex. Usage of inhaled steroids was defined as: none, low dose (<400 µg daily), intermediate dose (between 400 and 800 µg daily) and high dose (>800 µg daily). Based on presumed differences in effectiveness and deposition the dosage of a dry powder inhaler was halved to obtain equipotent dosages with metered dose inhalers⁹. The cut-off points for fluticasone were <125, between 125 and 250 and

>250 µg daily for low, intermediate and high doses, respectively. Occupational status was defined as being unemployed versus having a regular (part time) job or study. Each of the factors was first studied univariate using the Pearson chi-square test for categorical variables and the Student's t-test for age. All factors with an alpha <0.05 were included in a multivariate logistic regression by stepwise forward inclusion of each separate factor and all first-degree interactions between factors identified. The log-likelihood method was used with a threshold of 0.05 for inclusion of each factor. Analysis was performed using the SPSS 9 software package¹⁰.

Results

A total number of 283 patients were invited by their GPs and 148 (52%) were willing to participate. In table 4.2, the relation between use of inhaled steroids and willingness to participate is summarised. The percentage of non-participants is relatively high in subjects not using inhaled steroids (although they should) and there is a reciprocal relationship between dosage of inhaled steroids and willingness to participate (Pearson chi square 61.94, $p < 0.0001$). Based on the selection criteria defined, all selected patients should require inhaled corticosteroids. However, 143 (51%) of all selected patients were not using inhaled steroids at the time of selection. Within this group, 43 patients (43/143 is 30%) were willing to participate. From all patients who did use inhaled steroids, 105 out of 140 (75%) were willing to participate.

Table 4.2: Willingness to participate and the dosage of inhaled steroids (Pearson chi-square=61.94, $p < 0.0001$)

	Willing to participate (%)	Not willing to participate (%)
No inhaled steroids	43 (30)	100 (70)
Low dosage of inhaled steroids	44 (81)	10 (19)
Intermediate dosage of inhaled steroids	43 (78)	12 (22)
High dosage of inhaled steroids	18 (58)	13 (42)
Total no of subjects	148 (52)	135 (48)

The relation between occupational status and willingness to participate is outlined in Table 4.3. Unemployed subjects have a higher tendency to participate (Pearson chi square 16.32, $p < 0.0001$).

The mean age of participants and non-participants were 38 and 36, respectively ($p = 0.078$, t-test). Within the female group, 95 of 181 subjects (53%) were willing to participate, within the male group this was 53 out of 102 (52%) (Pearson chi square 0.01, p -value = 0.932).

Table 4.3: Willingness to participate and occupational status (Pearson chi-square=16.320, $p < 0.0001$)

	Willing to participate (%)	Not willing to participate (%)
Unemployed	37 (69)	17 (31)
Regular job or study	89 (55)	73 (45)
Unknown	22 (33)	45 (67)
Total no of subjects	148 (52)	135 (48)

Based on the above findings, a multivariate logistic regression model was tested with dosage of inhaled steroids, occupational status and age. Usage of inhaled steroids and occupational status were statistically significant independent determinants of willingness to participate. There were no significant interactions. Table 4.4 gives the results of the tested model.

Discussion

In this study, dosage of inhaled steroids and occupational status were identified as independent factors associated with willingness to start asthma self-management. In general, half of all invited asthmatics are willing to participate.

In a focus group study exploring views of asthma patients on self-management, Jones et al. found that 34 out of 35 patients stated that these plans were not relevant for them personally¹¹. This is in contrast to our results and to findings by Paterson et al.¹², who interviewed 120 patients from a nurse run asthma clinic in general practice. The majority of patients interviewed were in favour of asthma care

Table 4.4: Relation between dosage of inhaled steroids, occupational status and willingness to participate: multivariate logistic model

	Odds ratio	95% confidence interval
Dosage of inhaled steroids		
None	0	
Low	10.59	4.70 – 23.88
Intermediate	8.39	3.82 – 18.35
High	3.06	1.33 – 7.04
Occupational status		
Unemployed	0	
Regular job / education	0.40	0.19 – 0.84
Unknown	0.39	0.17 – 0.91

aiming to teach people to manage their asthma for themselves. Additionally, in a Dutch outpatient clinic population willingness to participate in a self-management programme was 68%¹³. This comes close to our findings that the participation rate was 75% within the group of subjects already using inhaled steroids.

The finding that willingness to participate is lower in patients with high dosages of inhaled steroids supports our hypothesis that these patients are truly steroid dependant. Other studies have shown that discontinuation of inhaled steroids is often accompanied by exacerbations⁷. On the other hand, there is a substantial group of patients in whom periodic treatment^{14,15} or at least dose reduction⁷ has proved possible.

One of the most striking findings in our study was that 51% of invited patients did not use inhaled steroids, although they should, on the basis of the criteria defined. These criteria were based on national guidelines for general practice^{16 17}, which are in this respect comparable to international guidelines^{3,18}. Willingness to participate appears to be associated with prescription of inhaled steroids. This is an important finding, which may be explained by selection criteria used in this study. GPs were instructed to include all patients possibly requiring inhaled steroids in their invitation list. Based on information sources used, GPs could not properly estimate the need for

inhaled steroids in all cases. As patients who were not willing to participate did not visit the lung function laboratory we could not verify their actual need for inhaled steroids. It is justifiable that patients who can do without inhaled steroids are unwilling to participate. Although it seems obvious that these subjects will be least willing to participate, this may be an oversimplification. Willingness to participate may also depend on reasons for not using inhaled steroids (e.g. steroid resistance, non-compliance) and whether these can be modified or not.

Another factor identified in this study was the role of occupational status. The finding that occupational status was not always known to the GP hampers interpretation of our findings. If the unknown group consists of a relatively high number of unemployed subjects, the difference found might decrease or even disappear. If there is a relatively high number of subjects with a regular job or education, the difference observed could become even more prominent. Based on our findings, the initial observation that patients with a regular job were more reluctant to participate in a self-management program seems true, but generalisation to all asthma patients is uncertain.

In our study, we may have underestimated willingness to participate, because two of our exclusion criteria: the presence of exacerbations one month prior to the study and the presence of other diseases that influence bronchial symptoms. Earlier studies indicate that patients are more accessible for a new treatment strategy closely after having had an exacerbation and in the presence of comorbidity¹⁹. Especially for patients unjustly not using inhaled steroids, willingness to participate may have been higher had patients with a recent exacerbation been included.

This study certainly does not cover all possible factors influencing the willingness of patients to participate in self-management programmes. However, factors identified in this study are all easily accessible for the GP, making them relevant for a quick assessment. Based on our findings, we recommend the procedure summarised in Table 4.5 to select and invite patients possibly interested in self-management in general practice.

Finally, results from this study show that most patients are interested in self-management plans. Acceptance of guided self-management plans by patients is therefore not a limiting issue in promoting the usage of self-management of asthma.

Table 4.5: Identification and assessment of asthma patients possibly interested in self-management.

STEP 1	STEP 2	STEP 3	STEP 4
Identify asthmatics:	Assess current steroids	Assess need for inhaled steroids	Advised action
Information sources: problem list codings	No inhaled steroids	Not required	No further action
Current prescription		Required	First discuss with patient and initiate treatment
Influenza campaign list	Low-intermediate dosage		Offer self-management program
	High dosage	Earlier reduction failed	No further action
		Dosage reduction might be possible	First discuss dose reduction

Patients on low or intermediate dosages of inhaled steroids were most willing to participate. As this group is predominantly treated in general practice, high acceptance of self-management in this category of patients makes general practice the most appropriate setting for this treatment strategy.

References

1. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ et al. Self-management education and regular practitioner review for adults with asthma [Cochrane Review]. The Cochrane Library Issue 3. 2000. Oxford: Update Software.
2. Thoonen BPA, Schermer TRJ, van den Boom G, van Schayck CP. Self-management of asthma in general practice [abstract]. 16TH WONCA World Congress of Family Doctors 2001.
3. Meijer RJ, Kerstjens HA, Postma DS. Comparison of guidelines and self-management plans in asthma. *Eur Resp J* 1997;10(5):1163-72.
4. Thoonen BPA, Jones KP, van Rooij HA, van den Hout AC, Smeele I, Grol R et al. Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view. *Fam Pract* 1999;16(2):117-22.
5. Bosley CM, Fosbury JA, Cochrane GM. The psychological factors associated with poor compliance with treatment in asthma. *Eur Respir J* 1995;8(6):899-904.
6. van Grunsven PM, van Schayck CP, van Kollenburg HJ, van Bosheide K, van den Hoogen HJ, Molema J et al. The role of "fear of corticosteroids" in nonparticipation in early intervention with inhaled corticosteroids in asthma and COPD in general practice. *Eur Respir J* 1998;11(5):1178-81.
7. Haahtela T, Jarvinnen M, Kava T, Kiviranta K, Koskinen S, Lehtonen K et al. Effects of reducing or discontinuing inhaled budesonide in patients with mild asthma. *New Engl J Med* 1994;331(11):700-5.
8. den Otter J, ter Horst H, van Schayck C, Thoonen B, Molema J, van Weel C. Self-management asthma programs: determinants of willingness to participate. [abstract]. *ATS* 1996.
9. Lipworth BJ. Pharmacokinetics of inhaled drugs [comments]. *Br J Clin Pharmacol* 1996;42(6):697-705.
10. SPSS for Windows. 1999.
11. Jones A, Pill R, Adams S. Qualitative study of views of health professionals and patients on guided self-management plans for asthma. *BMJ* 2000;321(7275):1507-10.
12. Paterson C, Britten N. Organising primary health care for people with asthma: the patient's perspective. *Br J Gen Pract* 2000;50(453):299-303.

13. van der Palen J, Klein JJ. Self-management of asthma by adults. Development and evaluation of a program with an emphasis on self-treatment of exacerbations [thesis]. Medisch Spectrum Twente, 1998.
14. van Schayck CP. Risks and benefits of periodic treatment of asthma with inhaled steroids BioDrugs 1997;7(1):1-5.
15. van Schayck CP. Periodic treatment regimens with inhaled steroids in asthma or chronic obstructive pulmonary disease; Is it possible? JAMA 1995;274(2):161-4.
16. Geijer RMM, van Hensbergen W, Bottema BJAM, van Schayck CP, Sachs APE, Smeele IJM et al. NHG-Standaard astma bij volwassenen: behandeling (NHG Guideline on asthma in adults: treatment) Huisarts Wet 1997;40(9):443-54.
17. van der Waart MAC, Dekker FW, Nijhoff S, Thiadens HA, van Weel C, Helder M et al. NHG-standaard CARA bij volwassenen: behandeling (NHG Guideline on CNSLD in adults: treatment). Huisarts Wet 1992;35(11):437-43.
18. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. Thorax 1997; 52(Supplement 1):S1-S21.
19. Barner JC, Mason HL, Murray MD. Assessment of asthma patients' willingness to pay for and give time to an asthma self-management program. Clin Ther 1999;21(5):878-94.

Asthma education tailored to individual patient needs can optimise partnerships in asthma self-management

Bart PA Thoonen¹, Tjard RJ Schermer¹, Margreet Jansen², Ivo Smeele¹, Annelies JE Jacobs³, Richard Grol³, Onno CP van Schayck⁴

¹ Dept of General Practice / Family Medicine, University Medical Centre Nijmegen, The Netherlands

² Dept of General Practice / Family Medicine, University of Maastricht, The Netherlands

³ Centre for Quality of Care Research, Universities of Nijmegen and Maastricht, The Netherlands

⁴ At the time of the trial: Dept of General Practice / Family Medicine, University Medical Centre Nijmegen, The Netherlands. Currently: Dept of General Practice / Family Medicine, University of Maastricht, The Netherlands

Published in: Patient Education and Counseling 2002;47:355-60

Abstract published as: Thoonen BPA, Schermer TRJ, Schayck CP van.

Self-managed education diminishes the risk of underestimating information needs of asthma patients. Asthma in General Practice 2000;9 supplement:S20

Abstract

This paper studies the effects of patient education, tailored to individual needs of patients as part of an asthma self-management program. A tailored education program was designed which took into account individual information needs of patients by using a feedback instrument. Totally 98 steroid dependent asthmatics entered the tailored education program, 95 patients received usual care. Outcome measures were information exchanged and patient satisfaction. Study duration was 6 months. Patients in the tailored education group showed a significant reduction in information need ($p=0.005$). Patient satisfaction increased from 87.9 to 93.7 in this group while this did not change in the usual care group ($p=0.000$). Use of this tailored education program improved the GP-patient interaction within the context of a clinically effective asthma self-management program. Findings from this study may be applicable to other chronic conditions as well.

Introduction

Management of chronic diseases has changed during the last few decades. Especially the introduction of evidence based guidelines caused a shift from symptom based management towards disease management¹⁻⁴. Specific aspects of chronicity like relapse prevention, maintenance therapy and scheduled follow-up have led to changes in the long-term outcome of chronic diseases. But the apparent gap between effectiveness and efficacy demonstrates that other factors than adequate diagnostics and therapy may determine the success of chronic disease management. One factor that remains underestimated in most studies is the role of the patient in terms of adherence to any given treatment program or advice. A suitable tool to alter adherence is appropriate patient education combined with skills training and a self treatment plan⁵⁻⁹. A major problem regarding patient education however is the discrepancy between what the patient needs to know according to the health professional and what the patient wants to know on the basis of own interests or previous knowledge. Patient education aimed at improving compliance is often based on the aforementioned 'need to know' basis and has the potential risk of becoming yet another way of pursuing professional objectives¹⁰. This makes it obvious that patient-education should be tailored to individual needs.

One of the chronic conditions in which success of a structured disease management plan depends greatly on adherence and involvement of patients is asthma. Previously to this study 28 relevant topics ('need to know') for asthma education were identified by a panel of GP's, based on a Delphi consensus procedure¹¹. As part of an asthma self-management plan a stepwise education program was designed, based on these topics. This asthma self-management program improved quality of life and asthma control^{12;13}. In terms of cost-effectiveness it proved to be a dominant treatment strategy¹⁴. Patients were given a tool to indicate to the GP what they wanted to know themselves about their asthma (feedback) and thus influenced the contents of their own asthma education. Because of the increased involvement of the patient in his or her own education this approach was called tailored education. The objectives of the tailored education program were to provide asthma education as defined by the Delphi procedure and to meet the specific information need of the patient as well. To find out if this could be achieved we studied if use of feedback by patients led to a decrease in information needs of patients. We also investigated if the education program led to changes in satisfaction of patients with the treatment of asthma as provided by their GP.

Methods

Study design

Main outcome measures of the education program were changes in patient satisfaction and the information need of patients. The design of the study is schematically summarised in figure 5.1.

A total number of 19 practices participated in this study. Self-management intervenes in the interaction between health care professionals and their patients. To prevent contamination within family practices it was therefor considered important that all patients in each practice received the same treatment. Randomisation thus took place at practice level.

Figure 5.1: Schematic representation of the trial comparing the effectiveness of a self-management program and usual care.

	0 weeks	2 weeks	4 weeks		3 months		6 months
Self management	Edu1 PatSat	Edu2	Edu3		Edu4		Patsat
Usual care	Patsat						Patsat

Edu1..4: Scheduled education sessions

PatSat: Patient Satisfaction questionnaire

Inclusion of patients

GPs selected all known asthma patients from their own practice population. Patients had to be aged between 16 and 60 years and had to have a need for inhaled corticosteroids, based on criteria from national guidelines on the treatment of asthma[15]. At the lung function laboratory patients were checked for in- and exclusion criteria, which have been described in detail elsewhere[16]. Permission was given by the local medical ethical committee.

Tailored education and usual care

The tailored education program consisted of four individual sessions by the GP: an initial session of 30 min and three repeated education sessions of respectively 20 min and 2 sessions of 10 min. As indicated in figure 5.1 all sessions took place within a period of 3 months. Topics that had to be discussed in each consequent session were written down in a protocol for the GP. GPs received this protocol together with oral instructions before the start of the study. After completion of all four sessions according to the protocol, the following topics had been discussed with the patient: mechanisms and causes of asthma, skills training (peak-flow measurement and inhalation technique), pharmacological and non-pharmacological treatment and instructions on when and how to stepwise stop, halve or double the dosage of inhaled steroids. These issues are already advocated by guidelines. In this study, all issues were systematically presented to all patients and their individual feedback was incorporated. Ten minutes before each subsequent session, the patient completed a feedback form. This is a list with 31 topics concerning asthma that was written in common language. The patient could indicate if he or she had received any

information at all about each topic, whether this information was sufficient, or if additional information was required. One of the obligatory items in the protocol for the GP was to make an inventory of and to discuss the needs of the patient, as they were indicated on the patient list. It was left to the responsibility of the GP if he or she discussed the topic immediately or postponed discussing the topic to a later session, as long as the latter was made explicit towards the patient.

In the usual care group GPs were instructed to treat all asthma patients according to current local guidelines^{2;15}. At the start of the program one visit at the GP office was scheduled in order to provide standardised instructions to patients on use and dosage of their inhaled steroids (budesonide 200 µg Turbuhaler ®).

Measures

Changes in information needs were measured by comparing the counts per patient of items with answer categories 'I know all I need to', 'I want to know more' and 'I did not receive any information' before the first and the third repeated education session. As these counts were normally distributed differences were tested by a T-test for paired samples.

The need for additional information was also studied for each separate topic. Before the first and the third repeated education session the percentage of patients indicating a need for additional information for each answer category was calculated. Confidence intervals (CIs, 95%) were calculated for the differences in these percentages to test for statistically significant changes in information need. Handing over a list of topics concerning asthma in itself stimulates the need for additional information in patients. Therefore, the need for information was not assessed within the usual care group in order to avoid induction of information needs.

Patient satisfaction was measured before the start of the study. To minimise the effects on patient satisfaction due to the extra time spent on educating the tailored education group (Hawthorne effect), patient satisfaction was measured again 3 months after finishing the tailored education program. This was 6 months after the start of the study (figure 5.1). To assess if patients were satisfied with the care given by the GP a 20-item questionnaire was derived from the CEP-questionnaire¹⁷⁻²¹. This CEP-questionnaire was especially designed to measure the patients' opinion about

several aspects of the treatment provided by their GP. The CEP-questionnaire includes nine dimensions of general practice care. Of those dimensions only 'medical care', 'relation and communication' and 'information and advice' were used, as they were seen as the most relevant in relation to the contents of the education program. Satisfaction for each item was measured on an ordinal scale from 1 to 6 points (1=least satisfied, 6=most satisfied). To measure patient satisfaction, first a principal components factor analysis was performed on all 20 questions. One factor containing all 20 questions explaining 54% of variance was identified. As the correlation for all variables in this factor was at least 0.6 an overall score was calculated by adding the scores of each individual question. This overall score was used to measure changes in patient satisfaction. All questions were also compared separately to identify which items specifically changed. There were no significant differences in baseline satisfaction scores. Therefore, the difference in scores at the start of the study and after 6 months were compared. Changes in mean satisfaction score of at least 0.5 for each item within one of both groups were considered relevant. As no previous experience with changes in satisfaction scores was present, this limit was set arbitrarily.

Results

Sample

After the selection procedure 214 eligible patients were included, 104 in the usual care group and 110 in the tailored education group. In the tailored education group seven patients did not start with the program and five patients decided to stop during the education program. As a result 98 patients completed the education program. In the usual care group eight patients did not start and one patient decided to stop, leaving 95 patients. Baseline characteristics of patients completing the tailored education program are summarised in table 5.1. Interviews with participating GPs after the selection procedure did not reveal any possible selection-bias in terms of excluding patients on other reasons than the study criteria.

Table 5.1. Baseline characteristics of study subjects¹.

	Self-management (n = 98)	Usual care (n = 95)	p value
Age (years)	39.6 (11.2)	39.3 (12.0)	0.859
Sex (male/female)	34/64	40/56	0.394
Packyears ^a	5.8 (4.5)	5.7 (4.5)	0.881
Duration of asthma ^b (years)	21.0 (16.5)	18.1 (14.3)	0.232
FEV ₁ (L)			
Before bronchodilator ^c	2.80 (0.66)	3.00 (0.76)	0.044
After bronchodilator	2.99 (0.67)	3.20 (0.77)	0.051
FEV ₁ as % of predicted value			
Before bronchodilator ^c	84.0 (13.1)	86.9 (14.2)	0.141
After bronchodilator	90.0 (12.1)	92.6 (12.9)	0.135
Bronchial hyperresponsiveness (PC ₂₀ -histamine, geometric mean)	1.10	1.05	0.144

¹: Figures are means (SD) unless stated otherwise.

FEV₁=forced expiratory volume in one second in litres

^a missing data - SM 2; UC 1

^b missing data - SM 17; UC 14

^c missing data - SM 1

Changes in information need

Table 5.2 summarises changes in information needs based on each answer category. There was a statistically significant reduction in the number of items with answer categories 'I want to know more' and 'I did not receive any information'. Additionally, there was a statistically significant increase in the number of items with answer category 'I know enough'.

Table 5.3 summarises the number of patients asking for additional information for each separate topic after the first visit. The reduction in percentage of patients needing additional information after 3 months is also summarised in table 5.3. All items showed a significant decrease in the need for additional information except 'Training of peak flow measurement'. Remarkable are the pronounced interests in the prognosis of asthma and the effects of asthma medication. Also, remarkable is

the lack of interest in peak-flow measurement, which is one of the cornerstones of our asthma self-treatment plan.

Table 5.2: Changes in information need for each answer category

	Mean number of items per patient (95% confidence interval) for each answer category		
	'I want to know more'	'I know enough'	'I didn't receive any information'
	(p=0.005)	(p=0.001)	(p=0.003)
Before first repeated education session	5.9 (5.0 – 6.9)	20.0 (18.6 – 21.4)	4.0 (3.1 – 4.9)
Before third repeated education session	0.7 (0.3 – 1.1)	25.6 (23.5 – 27.6)	1.0 (0.4 – 1.7)

Table 5.3: Changes in the number of patients needing information per topic

Topic	Need for information at first repeated education session (% of patients)	Reduction in information need between first and third repeated education session (% change with 95% confidence interval)
Prognosis of asthma	45	37 (26 – 48)
Side effects of inhaled steroids	45	41 (29 – 53)
How and why to change dosage of inhaled steroids	37	31 (20 – 42)
Only long term effect of inhaled steroids	32	29 (19 – 39)
Role of patient platforms	33	27 (17 – 37)

Relation between physical exercise and symptoms	30	26 (16 – 36)
Effect of long-acting bronchodilators	26	24 (16 – 34)
Effect of short-term bronchodilators	24	24 (15 – 33)
Hyperreactivity and personal triggers	23	23 (14 – 32)
When and how to take prednisone tablets	23	17 (7 – 27)
Nature, cause and prevention of allergy	21	19 (11 – 27)
Effects of oral steroids	21	16 (8 – 27)
Occupational advice and role of a company doctor	19	17 (9 – 26)
Effects of inhaled steroids	18	18 (10 – 26)
Nature, cause and prevention of exercise induced asthma	18	16 (7 – 24)
Sanitation at home	17	13 (6 – 20)
Possible causes of asthma	17	11 (2 – 19)
Goals of asthma management	16	14 (6 – 23)
Possible reasons for referral to specialist	14	12 (4 – 20)
Importance of proper inhalation technique	13	13 (6 – 21)
Importance of influenza vaccination	13	13 (6 – 21)
Effects of (passive) smoking	13	11 (4 – 17)
Additional medication	12	11 (3 – 18)
Basic characteristics of asthma	11	10 (2 – 17)
Mechanism of shortness of breath	10	8 (2 – 15)
Importance of regular follow-up	9	6 (1 – 11)
Information about intracutaneous allergy test	7	7 (2 – 13)
Information about lung-function test	6	6 (1 – 11)
Training of peak-flow measurement	4	4 (0 – 8)

Patient satisfaction

The overall scores for the patient satisfaction in both groups are summarised in table 5.4. As this table shows, both within the tailored education group and between the tailored education and the usual care group significant changes occurred. Questions with both statistically and clinically significant improvements in patient satisfaction were: 'Did your GP convince you of the importance of taking medicines?', 'Does your GP help you to deal with your disease(s)?', 'Do you know enough of your disease to manage at home?', 'Did your GP convince you to follow his/her advice?', 'Does your GP pay attention to the consequences of your disease in daily life?', 'Does your GP involve you in looking for an explanation of your symptoms?', 'Does your GP reassure you with regard to your symptoms?' and 'Does your GP perform no more tests than necessary'.

Table 5.4: Patient satisfaction scores before and 6 months after the education program*.

	Before program (95% confidence interval)	After six months (95% confidence interval)
Tailored education	87.90 (80.09 – 89.11)	93.69 (89.63 – 97.76)
Usual care	84.26 (80.10 – 88.42)	84.23 (80.16 – 88.30)

*: Patient satisfaction scores: 0 means least satisfied, 120 means most satisfied on all items

Discussion and conclusion

Discussion

Results of this study show that GPs are able to reduce the information needs of asthma patients using feedback of information needs, resulting in a higher patient satisfaction. This is also reflected in the decrease of the need for additional information as described for each separate item in table 5.3.

A similar approach was tested by Cegala et al^{22;23}. They provided patients with tools to make a systematic inventory of their information needs combined with a communication-training booklet. They demonstrated that this approach was capable of improving information seeking behaviour of patients and compliance. In our study we added an information checklist for patients to assist them in making an inventory in their information needs. This was based on the presumption that this checklist notifies patients of the existence of all possibly relevant topics as interest in certain topics needs to be preceded by the awareness of their existence. Thus, the role of GPs in educating asthma patients is to increase the awareness of the existence and importance of certain information. Next, it may depend on the relevance to the patient if the presented topic deserves further discussion.

Additionally, it must be notified that information needs as indicated by patients should not be used as a touchstone of their actual knowledge. One of the cornerstones of our self-treatment plan is the regular (daily - weekly) assessment of peak flow values. From our data it appears that patients have a remarkable low interest in this topic, which does not change throughout the education program. Other topics that are associated with (self) management, like the importance of an adequate inhalation technique and effects of (passive) smoking show the same pattern. This either means that patients believe they know enough about these topics, or they are not interested in them. As patients record their information need for the first time after the baseline visit to the GP a baseline need for information may already have been fulfilled. For the afore-mentioned topics over 75% of the patients indicated at the first repeated education session that they had sufficient information about these topics. Therefore little room is left to improve or to induce any need for additional information. So interest for these topics is low because patients thought they already knew enough about these items. This does not imply that patients are in fact well-informed about these issues and it should be left to the professional responsibility of the GP to verify if knowledge of the patient is sufficient indeed. Especially as interest in subjects like peak-flow measurement and inhaler technique is notoriously low in patients. As is shown in table 5.3 the information need of patients is highest for items related to personal fears and concerns like 'the prognosis of asthma' and 'side effects of inhaled steroids'. These findings confirm our

hypothesis that patients and health care providers are likely to have diverging agendas. In our study, providing patients with tools to elucidate their own needs and demands was associated with an increase in patient satisfaction. Our results are comparable to findings by vd Borne and co-workers²⁴ who tested a similar approach in an outpatient clinic setting. It also supports the findings from Little et al²⁵. They showed that communication aimed at understanding the patients' needs and worries is an important domain of patient centeredness. Patient and GP have a shared responsibility in managing the patient's asthma. The patient is responsible for focusing the GP to his or her needs, and the GP has the responsibility to enhance patients in expressing their own needs and to make patients aware of topics that are potential interest. As was demonstrated by Galefoss and Bakke such a patient centered approach is also beneficial from the GPs' perspective in terms of improved compliance and a reduction in the need for short acting bronchodilators⁶. We believe that systematically and actively involving patients in clarifying their personal needs does increase the patient's involvement in the management of his or her asthma and that this sharing of responsibilities is a prerequisite for effective (asthma) self-management.

Taking the results of the patient satisfaction questionnaire into account it is reasonable to assume that asthma patients do feel more involved and that adherence may increase. A change of 0.5 point on the answering scale was considered as relevant. Several questions related to the teaching of self-management improved almost an entire point. Our data show that asthma patients are especially more satisfied about the explanation of their medication and the feasibility of advises given by the GP. This is also reflected in effects of our self-management program on asthma-specific quality of life (AQLQ). Improvements in the emotions domain were both statistically and clinically relevant, indicating that patients felt less insecure about the impact of asthma on their daily life¹².

Conclusion

Educating and motivating patients is crucial for a successful self-management program²⁶. Before effective treatment will be feasible, ownership of the treatment plan is essential – in particular ownership by patients¹⁰. This implies that their needs,

demands and expectations must be taken into account. Findings from this study show that the needs of the patient can be taken into account in a satisfactory way within the context of asthma self-management. Following the tailored education approach, the interaction between the GP and the patient improved.

Implications for practice

Using materials for systematically taking into account the patients' needs may enhance shared decision-making by balancing the patients' and the GP's perspective in a more patient centered approach²⁷. Consequently, the checklist for patients that was used in our self-management program has been made available through the Internet by the Dutch Asthma Foundation (www.astmafonds.nl).

The basic principles used in this program are not disease specific. Although the contents of the education program are disease specific, the concept of shared responsibilities and self-management as an other approach of the doctor-patient relation is not, so beneficial findings from this study may very well be applicable to other chronic conditions like diabetes or chronic heart failure.

References

1. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997;52(Supplement 1):S1-S21.
2. Geijer RMM, van Hensbergen W, Bottema BJAM, van Schayck CP, Sachs APE, Smeele IJM et al. NHG-Standaard astma bij volwassenen: behandeling (NHG guideline on asthma in adults: treatment). *Huisarts Wet* 1997;40:443-54.
3. Meijer RJ, Kerstjens HA, Postma DS. Comparison of guidelines and self management plans in asthma. *Eur Resp J* 1997;10:1163-72.
4. anonymous. Global strategy for asthma management and prevention NHLBI/WHO workshop report. National heart, lung and blood institute, 1995. 95-3659.
5. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ et al. Self-management education and regular practitioner review for adults with asthma (Cochrane Review). The Cochrane Library Issue 3. 2000. Oxford: Update Software.
6. Gallefoss F, Bakke PS. How does patient education and self-management among asthmatics and patients with chronic obstructive pulmonary disease affect medication. *Am J Respir Crit Care Med* 1999;160:2000-5.
7. van der Palen J, Klein JJ, Rovers MM. Compliance with inhaled medication and self-treatment guidelines following a self-management programme in adult asthmatics. *Eur Respir J* 1997;10:652-7.
8. Partridge MR. Delivering optimal care to the person with asthma: what are the key components and what do we mean by patient education? *Eur Respir J* 1995;8:298-305.
9. Cochrane GM. Impact of education on treatment compliance in patients with asthma. *Monaldi Arch Chest Dis* 1993;48:369-71.
10. Thoonen BPA, van Weel C. Role of family physicians in implementing asthma self-management programs. *Disease Management and Health Outcomes* 2001;10:141-6.
11. Jansen CCM, Grol R, Jacobs A. Voorlichting aan carapatienten. ontwikkeling en evaluatie van richtlijnen voor de huisarts (Patient education for COPD patients. Development and evaluation of guidelines for general practitioners). *Huisarts Wet* 1997;40:522-7.
12. Thoonen BPA, Schermer TRJ, van den Boom G, van Schayck CP. Self management of asthma in general practice (abstract). 16TH WONCA World Congress of Family Doctors Abstract Book. 2001: 204-5.

13. Thoonen BPA, Schermer TRJ, van Weel C, Grol R, van Schayck CP. Clinical effectiveness of self management of asthma in General Practice: a randomised controlled trial (abstract 3491). Eur Resp J 2001;18(S33):518S.
14. Schermer TRJ, Thoonen BPA, van den Boom G, Grol R, Folgering H, van Weel C et al. A randomised controlled economic evaluation of asthma self-management and usual care in general practice (abstract 3492). Eur Resp J 2001;18(S33):518S.
15. van der Waart MAC, Dekker FW, Nijhoff S, Thiadens HA, van Weel C, Helder M et al. NHG-standaard CARA bij volwassenen: behandeling [NHG Guideline on CNSLD in adults: treatment]. Huisarts Wet 1992;35:437-43.
16. Thoonen BPA, Schermer TRJ, Akkermans RP, den Otter JJ, Grol RP, van Schayck CP. Willingness of patients to perform self-management of asthma and the role of inhaled steroids. Scan J Prim Health Care 2002;20:60-4.
17. Grol R, Wensing M, Mainz J, Ferreira P, Hearnshaw H, Hjortdahl P et al. Patients' priorities with respect to general practice care: an international comparison. European Task Force on Patient Evaluations of General Practice (EUROPEP). Fam Pract 1999;16:4-11.
18. Wensing M, van de Vleuten C, Grol R, Felling A. The reliability of patients' judgements of care in general practice: how many questions and patients are needed? Qual Health Care 1997;6:80-5.
19. Wensing M, Grol R, Smits A, Van Montfort P. Evaluation of general practice care by chronically ill patients: effect of the method of administration. Fam Pract 1996;13:386-90.
20. Wensing M, Grol R, Van Montfort P, Smits A. Indicators of the quality of general practice care of patients with chronic illness: a step towards the real involvement of patients in the assessment of the quality of care. Qual Health Care 1996;5:73-80.
21. Wensing M. Patients evaluate general practice (thesis). University of Nijmegen, 1997.
22. Cegala DJ, Marinelli MT, Post DM. The effects of patient communication skills training on compliance. Arch Fam Med 2000;9:57-64.
23. Cegala DJ, McClure L., Mannelli MT, Post DM. The effects of communication skills training on patients' participation during medical interviews. Patient Educ Couns 2000;41:209-22.
24. Kruijff AF, van de Borne HW, Mesters I, Sterk PPH. Ondersteuning van de voorlichting tijdens een medisch consult. Een vragen- checklist voor astma- en copd-patienten (Support of patient education during office visits. A checklist for patients with asthma and COPD). Tijdschr Soc Gezondheidsz 1997;75:74-80.

25. Little P, Williamson I, Warner G, Moore M, Gould C, Ferrier K et al. Preferences of patients for patient centered approach to consultation in primary care: observational study. *Brit Med J* 2001;322:1-7.
26. Lahdensuo A. Guided self management of asthma--how to do it. *Brit Med J* 1999;319:759-60.
27. Fay JK, Jones A. Guided self management of asthma. More information is needed on what patients think about such management. *Brit Med J* 2000;320:249.

Chapter 6

Self management of asthma in general practice, asthma control and quality of life: a randomized controlled trial

BPA Thoonen¹, TRJ Schermer¹, G van den Boom¹, J Molema², H Folgering², RP Akkermans¹, R Grol³, C van Weel¹, CP van Schayck⁴

¹ Dept of General Practice / Family Medicine, University Medical Centre Nijmegen, The Netherlands

² University Lung Centre Dekkerswald, University Medical Centre Nijmegen, The Netherlands

³ Centre for Quality of Care Research, University of Maastricht and University Medical Centre Nijmegen, The Netherlands

⁴ At the time of the trial: Dept of General Practice / Family Medicine, University Medical Centre Nijmegen, The Netherlands. Currently: Dept of General Practice / Family Medicine, University of Maastricht, The Netherlands

Provisionally accepted: Thorax

Abstract

Background: Aim of this study was to assess the effects of a self-management program in general practice on asthma control, quality of life and lost-activity days.

Methods: Nineteen general practices were randomly allocated to usual care (UC) or self-management (SM). Asthma patients were included after confirmation of GP diagnosis. Follow up was two years. Patients kept diary cards and visited the lung function laboratory every six months. Outcomes were number of successfully treated weeks and limited activity days, asthma specific quality of life, FEV₁, FEV₁-reversibility, PC₂₀-histamine and amount of inhaled steroids.

Results: 214 patients were included (104 UC / 110 SM). Selected patients were predominantly female (62%). Mean percentage of successfully treated weeks per patient in the UC group was 72% (74 per 103 weeks) versus 78% (81 per 105 weeks) in the SM group ($p=0.003$). The average number of limited activity days was 1.2 (95% CI 0.5; 1.9) for self-management and 3.9 (95% CI 2.5; 5.4) for usual care. The estimated increase in asthma quality of life score was 0.10 points per visit in the UC group versus 0.21 points per visit in the SM group ($p=0.055$). FEV₁, FEV₁-reversibility and PC₂₀-histamine did not change. There was a saving of 217 puffs in favour of the SM group ($p<0.05$).

Conclusion: Self-management lowers the burden of illness as perceived by the patient and is at least equally effective as asthma treatment usually provided in Dutch primary care. Self-management is a safe basis for intermittent therapy with inhaled corticosteroids.

Introduction

Asthma is a chronic inflammatory pulmonary disease which has a significant socio-economic impact on patients and their family¹. The understanding that airway inflammation is the key underlying process has led to the early introduction of inhaled corticosteroids in the management of asthma²⁻⁵. Despite these guidelines and increasing insights asthma morbidity is still considerable. Poor compliance with prescribed inhaled therapy is an important cause of uncontrolled disease⁶⁻¹⁰. Poor control of asthma is associated with an impaired quality of life^{11;12} and is presumably

responsible for three quarters of the total costs of asthma¹. Therefore it is likely that improving compliance will lead to improvements in asthma control and quality of life. Low compliance results in underuse of (medication) care, but asthma is also characterised by overuse, in particular of inhaled medication. Overuse of inhaled steroids may increase the number of unwanted side effects, without additional benefits. There are indications that inhaled steroids can be tapered off or stopped during a certain period¹³ or at least reduced to the minimal effective daily dose that provides adequate control of the disease¹⁴. Optimising treatment for the individual patient may balance benefits and risks and leads to a more efficient and cost effective treatment. Mild asthmatics treated by their General Practitioner may be very suitable patients for intermittent therapy¹⁵, providing adequate control of their asthma is maintained. Implementing guided self-management takes a considerable effort¹⁶ and studies on effectiveness and use in General Practice are needed. As most published studies were effective in more severe asthmatics or in patients with frequent exacerbations, the question rises if guided self-management may also be effective in milder asthmatics. Loss of asthma control occurs less frequently and there is lower impact on quality of life¹⁷, leaving limited room for improvement. Aim of this study was to determine if guided self-management can provide a safe treatment strategy for asthma patients in General Practice.

Methods

Practices

Nineteen General Practices participated in this study. Stratified cluster randomisation was performed, based on the type of practice (solo, duo, group), the number of identified asthmatics (above or below the median number (14) of identified asthmatics) and use of computerised prescription (yes, no).

Selection of patients

GPs selected asthma patients aged between 16 and 60 years using problem list coding (ICPC), prescription data from practice records, the annual influenza vaccination campaign list, and prescription data provided by the local pharmacist.

Selected patients received an invitational letter from their GP. Patients willing to participate were checked by the investigators for the exclusion criteria as defined in Box 6.1. Those eligible for the study were invited for assessment in a lung function laboratory. Inclusion criteria are summarised in Box 6.1. Patients with a prebronchodilator FEV₁ less than 80% of predicted were treated with 800 µg budesonide bid during a six weeks run in period.

Box 6.1: In- and exclusion criteria

Exclusion criteria:

- Smoking history of 15 or more pack years
- Serious other diseases than asthma with a low survival rate
- The patient has had exacerbations during a period of one month before the start of the study
- Other diseases which influence bronchial symptoms and/or lung function (e.g. decompensatio cordis, sarcoidosis)
- The patient is unable to inhale medication correctly or to measure and record their peakflow adequately and it is unlikely that this can be taught.

Inclusion criteria:

Treated for asthma by the GP
and age between 16 and 60 years
and FEV₁ more than 40% of the predicted value and more than 55% of predicted 15 minutes after inhalation of 800 µg salbutamol or 6 weeks after inhalation of 800 µg budesonide twice daily
and reversibility FEV₁ (after bronchodilation with 800 µg salbutamol metered dose inhaler or 8 weeks treatment with 800 µg budesonide twice daily) of at least 10% of the predicted value or PC₂₀ histamine ≤ 8 mg/ml

Study medication

All included patients were treated with budesonide 200 mcg/dose dry powder inhaler (Turbuhaler®). In the self-management group patients were educated to change their dosage of inhaled steroids according to a written self-treatment plan (Box 6.2).

Box 6.2: Summary of the self-treatment plan.

Step-up instructions

- *Peak flow deteriorates $<80\%$ PEFR $\geq 60\%$ of Personal Best Value (PBV) for 2 out of 3 consecutive days:*
 - double budesonide dosage
 - in case of insufficient response within three weeks: again double budesonide dosage
- *Peak flow deteriorates $<60\%$ PEFR $\geq 40\%$ of PBV for 2 out of 3 consecutive days:*
 - increase budesonide dosage to 800 micrograms b.i.d.
 - in case of insufficient response within two days: start course of oral prednisolone
 - and contact your FP
- *Peak flow deteriorates $<40\%$ of PBV:*
 - If sufficient response to bronchodilator: start course of oral prednisolone
 - Else: immediately contact your GP

Step-down instructions

- *Peak flow improves to $\geq 40\%$ PEFR $<60\%$ of PBV:*
 - continue the current budesonide dosage until your PEFR is $>80\%$ of PBV
- *Peak flow improves to $\geq 60\%$ PEFR $<80\%$ PBV:*
 - continue the current budesonide dosage until your PEFR is $>80\%$ of PBV
- *Peak flow improves to $\geq 80\%$ of PBV:*
 - halve budesonide dosage when PEFR $\geq 80\%$ for a period of six weeks

In the usual care group the daily dosage was determined by the patients' GP according to the national guidelines for treatment of asthma^{18;19}. Both groups received regular inhalation instructions.

The self-management program and usual care

The self-management program started with four individual training visits at the GP office within a period of three months. These visits consisted of tailored education²⁰ and instructions on how to use a personalised written self-treatment plan. Patients weekly recorded morning and evening peak flow values and the presence of asthma symptoms. Three alarm symptoms were defined: waking at night because of asthma (yellow zone), use of bronchodilator >4 times a day (red zone) and increased dyspnea without exertion (purple zone). In the presence of alarm symptoms or a drop of peak flow values below 80, 60 or 40 percent of the personal best value, patients were instructed to start daily measurements of peak flow and symptoms. Self-treatment instructions for budesonide and oral steroids (30mg prednisolone per day, during 1 week) are summarised in Box 6.2. After the training visits biannual control visits were recommended over a follow-up period of 21 months. At each control visit GP's checked the patients' performance of the self-treatment instructions. It was left to the initiative of the GP and patient if and when these control visits took place. Training of inhalation technique and peak-flow measurement was repeated at each visit.

In the usual care group GPs were instructed to treat all asthma patients as usual, which is for most GPs according to the national guidelines of the Dutch College of Family physicians^{18;19}, which are largely comparable to most international guidelines, but which do not include self-management thus far. At the start of the program one visit at the GP office was scheduled to instruct patients on use and dosage of their inhaled steroids (budesonide 200mcg Turbuhaler ®).

Outcome measures

Main outcome measures of this study were asthma control, asthma specific quality of life and lost activity days. Asthma control was defined with the following parameters: percentage of successfully treated weeks; changes in post bronchodilator FEV₁

(800mcg salbutamol mdi through spacer); changes in reversibility of FEV₁ as percentage of the predicted value and the changes in PC₂₀-histamine.

Post bronchodilator FEV₁, reversibility and asthma specific quality of life were measured at baseline and each 6 months over a period of two years. PC₂₀-histamine²¹ was measured at baseline and after two years.

A successfully treated week was defined as a week in which acceptable asthma control in terms of perceived dyspnea was maintained. Patients in both groups weekly recorded dyspnea on a modified Borg-scale, ranging from 0 (no dyspnea) to 10 (maximally severe dyspnea)²². The median dyspnea score of all individual recordings was considered as cut off point between successfully and unsuccessfully treated weeks. Weeks with a dyspnea score equal to or below this cut-off point were counted as successful. To correct for differences in the number of recorded weeks, successfully treated weeks were standardised to the percentage of recorded weeks. An example of this procedure is graphically summarised for one patient in figure 6.1. In addition to the dyspnea scores patients weekly recorded the number of days during the last week with limited activities due to asthma.

Asthma specific quality of life was measured using the Asthma Quality of Life Questionnaire (AQLQ) by Juniper et al^{11;12}. An individual increase of 0.5 point of the overall score or one of the domain scores was considered a minimal clinically relevant improvement (MCRI).

Secondary outcome measures were the number of puffs budesonide used, the number of dose equivalents of short acting bronchodilators, short courses of oral prednisolone, antibiotics and GP-diagnosed exacerbations. The number of puffs budesonide used was counted at each laboratory visit by subtracting the number of remaining dosages in each turbuhaler issued from the total number of dosages prescribed over the past period. The amount of short acting bronchodilators was based on the weekly recordings of patients. Based on presumed differences in deposition between metered dose inhalers and dry powder inhalers, dry powder inhaler dosages were halved to get dose equivalents^{23;24}. Short acting bronchodilators were thus converted to equipotent doses of either salbutamol or ipratropium metered dose inhaler in micrograms per day.

Exacerbations were recorded by GPs at each (scheduled and unscheduled) visit. GPs recorded if there was an exacerbation according to their own professional judgement (based on symptoms, peak-flow and increased use of bronchodilators). Short courses of prednisolone and antibiotics prescribed were recorded as other indicators of exacerbations.

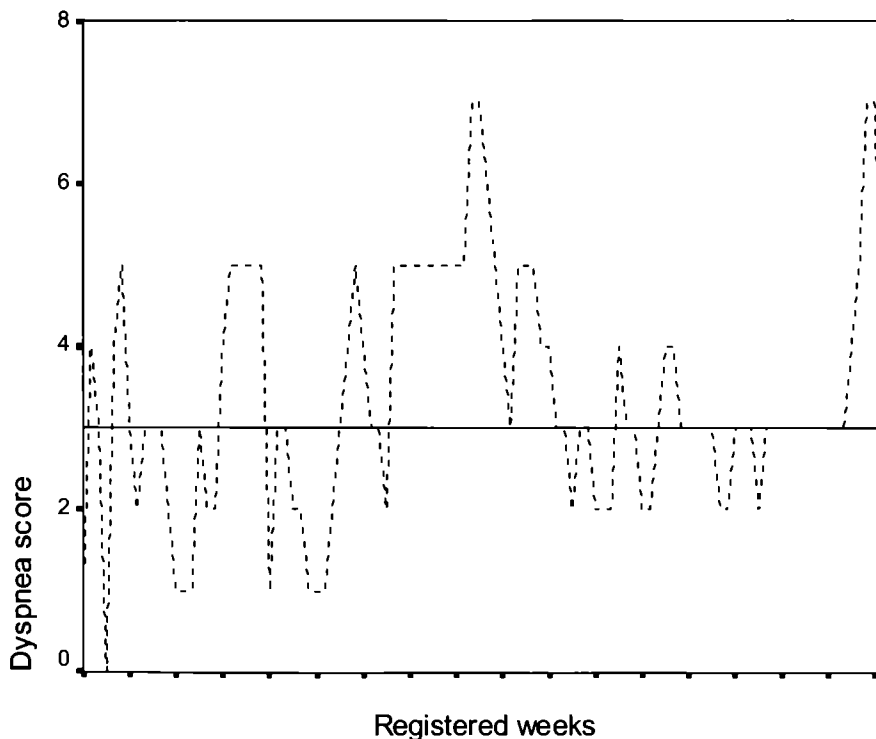
Figure 6.1: Calculation of successfully treated weeks for patient 09303 (usual care group).

No of registered weeks: 104

Median dyspnea score: 3

No of weeks with dyspnea < median dyspnea score: 64

Percentage of successfully treated weeks: $(64 / 104) * 100\% = 61.5\%$



Power calculation

The power calculation for determining the trial size was based on the asthma quality of life questionnaire. A between group change of 0.5 point was considered clinically relevant. Based on multilevel analysis, we assumed an average inclusion of 10 patients per practice and an interclass correlation of 0.02. With an observed standard deviation of 0.9, a power of 90% and an α of 0.05 (two sided), 17 practices with a total number of 170 patients were needed. When taking a drop-out rate of 20% after inclusion into account, 213 patients had to be initially included.

Analysis

Outcome parameters were evaluated on an intention to treat basis and by repeated measurement techniques²⁵. A random coefficient linear model with an autoregressive error structure (multilevel model) was performed on post BD FEV₁ and AQLQ. Reversibility FEV₁ (% predicted value) was analysed in a non-linear model. Baseline values, age, sex and smoking were entered as possible confounders. All analyses were performed using the PROC MIXED procedures by SAS²⁶. PC₂₀ values (²log transformed) were compared with a students-T-test. If there was a significant difference over time in any quality of life domain, the proportions of subjects with a relevant change (MCID) were compared too by Chi-square tests. Amounts of medication used in both groups and the percentages of successfully treated weeks were compared with a T-test when normally distributed and a Mann-Whitney U test when not normally distributed.

Results

Table 6.1 represents the characteristics of participating practices in both treatment groups. The flow chart in Figure 6.2 summarises the number of patients. During the pre-treatment phase 15 patients dropped out of the program and an additional 5 patients dropped out before the first follow-up measurement. Therefore 193 patients (98 self-management) were included in the intention to treat analysis. Baseline characteristics of patients included in the intention to treat analysis are listed in table 6.2. There was no difference in pre and post BD FEV₁ when corrected for age and sex. There were higher numbers of patients with asthma attacks during the previous

6 months and patients requiring pre-treatment in the self-management group. Asthma specific quality of life was lower in the self-management group for the activities and emotions domains.

Table 6.1: Practice characteristics

	Self-management	Usual care
Type of practices		
Solo	2 (25%)	1 (9%)
Duo	3 (37%)	5 (46%)
More than 2 GPs	3 (38%)	5 (45%)
Total	8	11
Number of asthmatics per 1000 patients	7.6	9.0
(95% CI)	5.6-9.6	4.9-13.2
Computerised prescription		
Yes/no	7/1	8/3

The mean percentage of successfully treated weeks per patient in the self-management group was 78% (95%-CI 75.1-80.6; 81 per 105 recorded weeks) versus 72% (95%-CI 68.8-74.8; 74 per 103 recorded weeks) in the usual care group. During follow-up 79% of self-management and 62% of usual care patients reported one or more limited activity days. When all patients were included, the mean number of limited activity days was 1.9 (95% CI 0.7; 3.2) for self-management and 6.0 (95% CI 2.6; 9.4) for usual care. Closer examination identified two distinct outliers in the usual care group with 142 limited activity days and 69 limited activity days, respectively. One of the outliers had a period of several months with frequent but short episodes of sick leave due to asthma, the other a three-month episode of uninterrupted sick leave. In both cases, irritant exposure in the workplace explained the high counts. Because of the clear work-related cause and the disproportionate impact of these two outliers on the group average we decided to exclude subjects above the 98th percentile from the final calculations in both groups.

This resulted in an average number of limited activity days of 1.2 (95% CI 0.5; 1.9) for self-management and 3.9 (2.5; 5.4) for usual care.

Table 6.2: Baseline characteristics of study subjects included in the intention to treat analyses. Figures are means (SD) unless stated otherwise.

	Self-management (n = 98)	Usual care (n = 95)	p value
Age (years)	39.6 (11.2)	39.3 (12.0)	0.859
Sex (male/female)	34/64	40/56	0.394
GSMoking			
Never GSMokers	45 (46%)	54 (56%)	
Former GSMokers	31 (32%)	21 (22%)	
Current GSMokers	22 (22%)	21 (22%)	0.254
Packyears ^a	5.8 (4.5)	5.7 (4.5)	0.881
requiring pre-treatment with budesonide [*]	34 (35%)	22 (23%)	0.077
% with asthma attack(s) in previous 6 months	48.5%	31.6%	0.017
FEV ₁ as % of predicted value			
Before bronchodilator ^b	84.0 (13.1)	86.9 (14.2)	0.141
After bronchodilator	90.0 (12.1)	92.6 (12.9)	0.135
FEV ₁ reversibility\$ (%) ^b (median)			
PostBD – preBD/predicted	5.0 (8.6) IQR	5.4 (6.8) IQR	0.930
Bronchial hyperresponsiveness			
PC ₂₀ geometric mean	1.20	0.97	0.442
Initial dose of inhaled steroids			0.622
none	12 (12%)	16 (17%)	
Low (<400 mcg daily, or equivalent)	36 (37%)	30 (32%)	
Intermediate (≥400 and <800 mcg daily, or equivalent)	34 (35%)	37 (39%)	
High (≥800 mcg daily or equivalent)	16 (16%)	12 (12%)	
Quality of life:			
Activities domain	5.3 (1.03)	5.6 (0.77)	0.015
Emotions domain	5.8 (1.01)	6.2 (0.76)	0.002
Symptoms domain	5.3 (1.03)	5.6 (0.90)	0.074
Environment domain	5.3 (1.10)	5.5 (1.1)	0.165
Overall score	5.4 (0.872)	5.7 (0.771)	0.013

FEV₁=forced expiratory volume in one second in litres; FVC=forced vital capacity

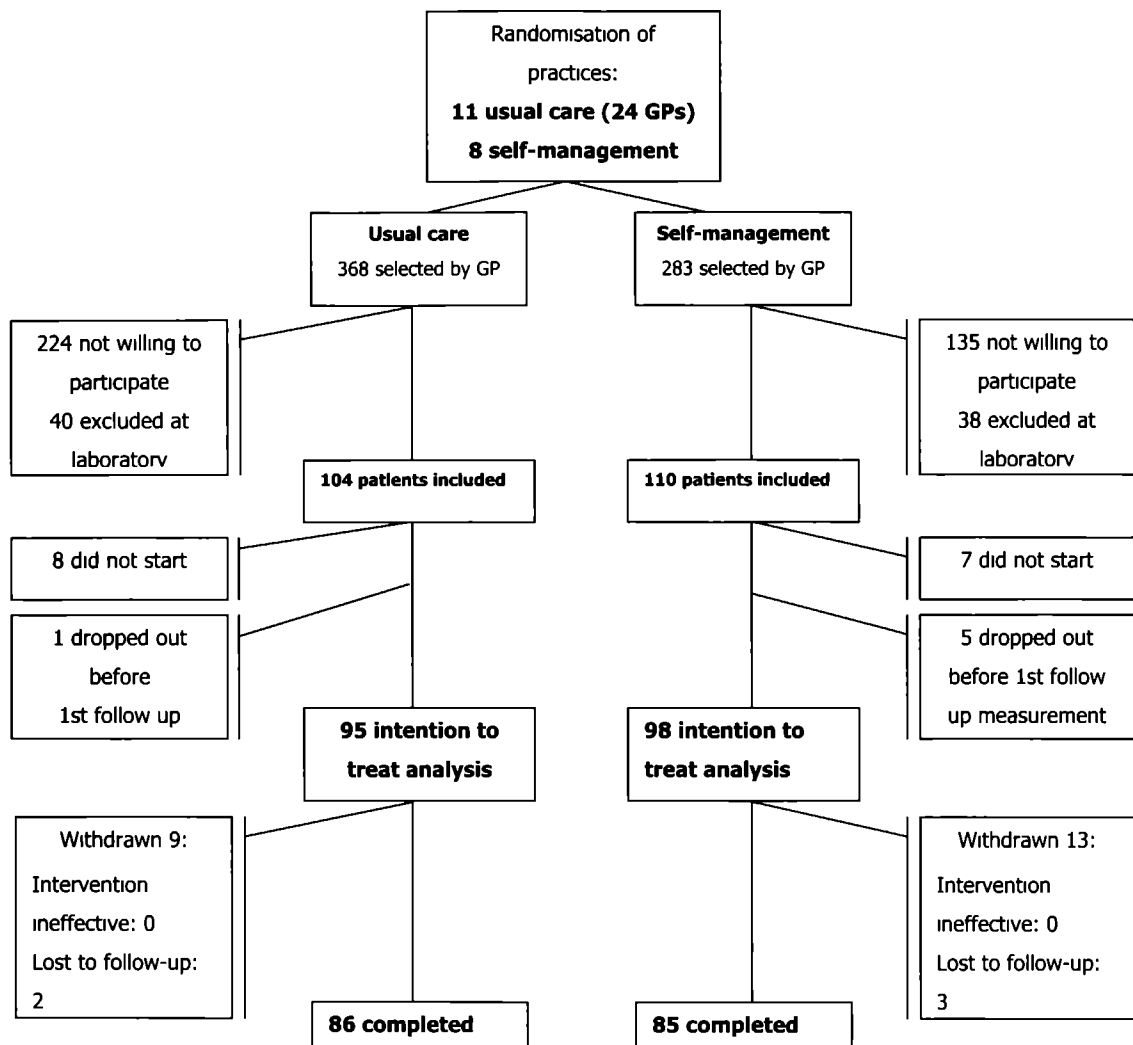
\$ difference between FEV₁ before and after bronchodilator/ predicted FEV₁

^{*} pre-treatment consisted of 6 weeks budesonide 800 micrograms BID

a) missing data - self-management 2; usual care 1

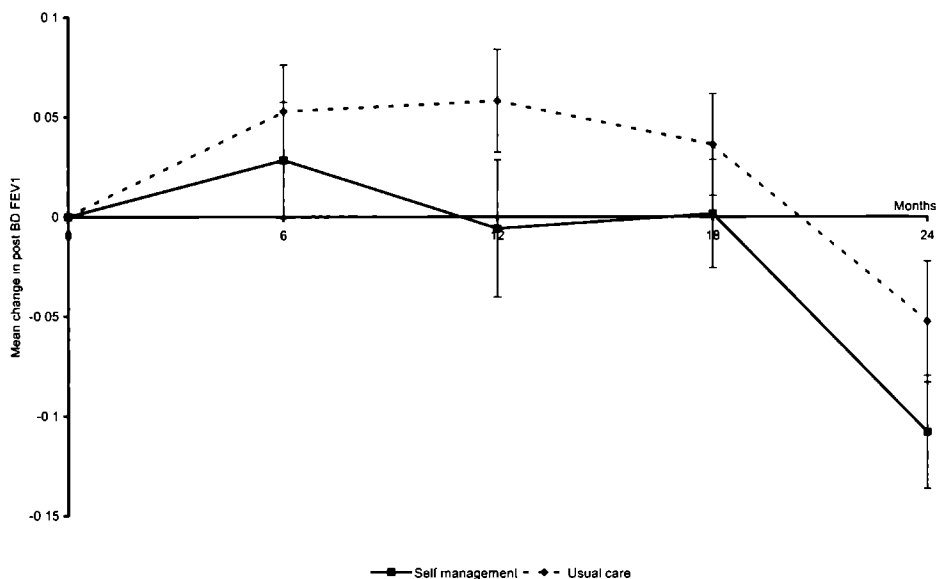
b) missing data - self-management 2, usual care 2

Figure 6.2: Flow chart of patients



As demonstrated in figure 6.3, the post bronchodilator FEV₁ showed an estimated decline rate of 0.048 L per year in the self-management group versus 0.026 L per year in the usual care group (p=0.239). There were no between-group differences in estimated decline-rate for FEV₁-reversibility and PC₂₀-histamine.

Figure 6.3: Mean changes from baseline in post bronchodilator FEV₁(L) with standard errors.



Changes from baseline in overall AQLQ-score are summarised in figure 6.4. Based on repeated measurements analysis the estimated increase in overall asthma quality of life score was 0.10 points per visit in the usual care group versus 0.21 points per visit in the self-management group (p=0.055). Changes in quality of life were also estimated for each of the sub-domains: emotions, activities, symptoms and environment. There only was a significant change between both groups in the emotions domain (0.02 points per visit in the usual care group; 0.20 points per visit in the self-management group; p=0.006), which is summarised in figure 6.5. To verify if statistically significant changes in quality of life were clinically relevant, we compared proportions of subjects with individual changes of at least 0.5 points. In the emotions domain 41% of patients from the self-management group had an

Figure 6.4: Mean changes from baseline in quality of life with standard errors

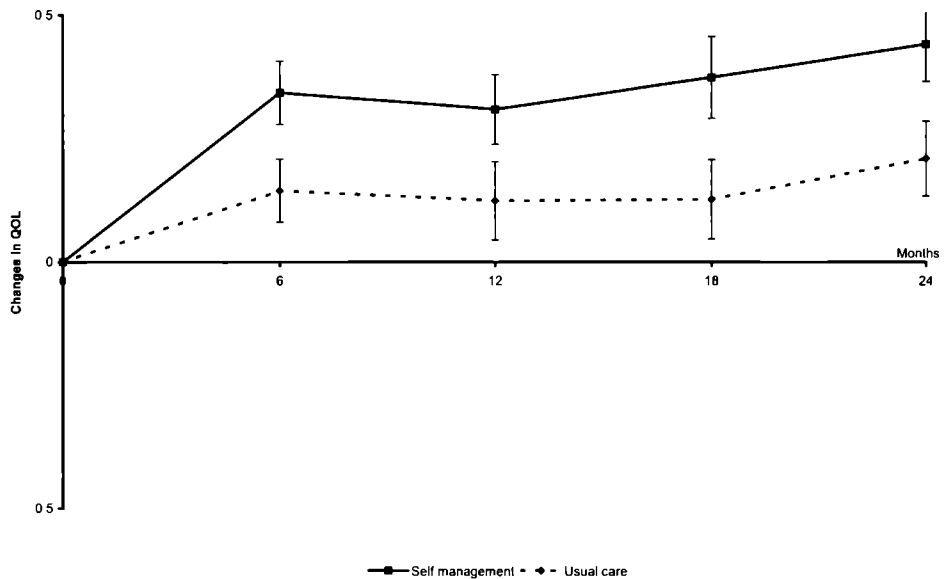
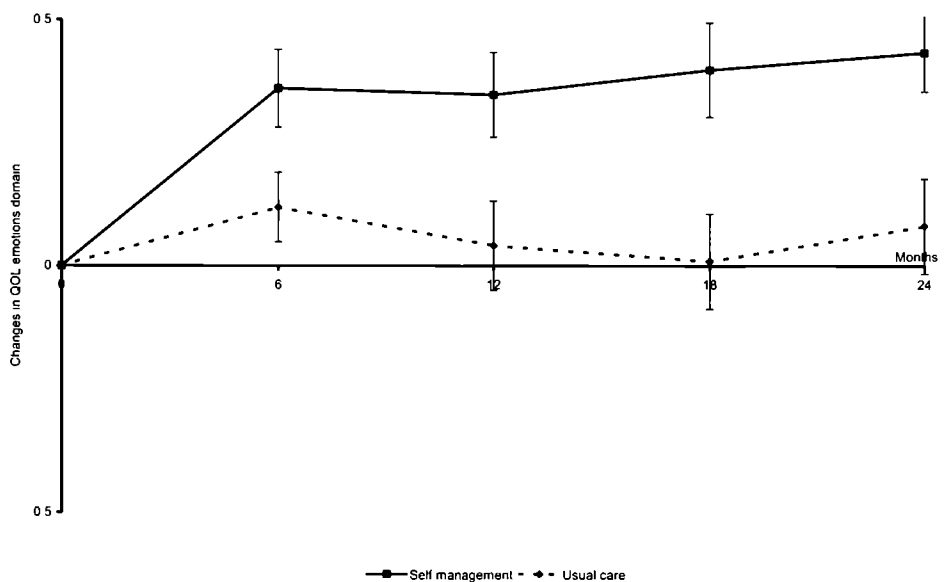


Figure 6.5: Mean changes from baseline in quality of life with standard errors, emotions domain.



increase of at least 0.5 point versus 23% of patients in the usual care group (Chi square=8.811, p=0.012).

Mean budesonide usage was 1680 puffs per patient (95% CI 1538; 1822) for self-management and 1897 puffs per patient (95% CI 1679; 2115) for usual care, indicating a saving of 217 puffs per patient.

With a median amount of 97 (168 IQR) micrograms per day of short acting beta-2 bronchodilators in the self-management group versus 69 (340 IQR) micrograms per day in the usual care group, there was no statistically significant difference between both study groups (p=0.711, Mann-Whitney-U). In the self-management group there was a median of 12 (28 IQR) micrograms per day of ipratropium versus 35 (114 IQR) micrograms in the usual care group (p=0.607, Mann-Whitney-U).

Table 6.3: Indicators of exacerbations.

(Between group comparison using Mann-Whitney-U test)

	Self- management	Usual Care
Exacerbations per patient per two years (p=0.678)		
No (% within group) with 0 exacerbations	29 (36)	33 (41)
No (% within group) with 1 exacerbations	28 (35)	22 (28)
No (% within group) with 2 exacerbations	7 (9)	12 (15)
No (% within group) with 3 exacerbations	7 (9)	6 (8)
No (% within group) with 4 or more exacerbations	9 (11)	7 (9)
Oral prednisolone courses per patient per two years (p=0.015)		
No (% within group) with 0 courses	64 (70)	80 (85)
No (% within group) with 1 course	19 (21)	11 (12)
No (% within group) with 2 courses	6 (7)	1 (1)
No (% within group) with 3 or more courses	2 (2)	2 (2)
Courses of antibiotics per patient per 2 years (p=0.643)		
No (% within group) with 0 courses	71 (78)	71 (76)
No (% within group) with 1 course	15 (17)	15 (16)
No (% within group) with 2 courses	2 (2)	5 (5)
No (% within group) with 3 or more courses	3 (3)	3 (3)

Table 6.3 summarises the indicators of exacerbations. There were no differences in the number of GP diagnosed exacerbations and the number of antibiotics. There was a statistically significant higher number of courses of oral prednisolone in the guided self-management group ($p=0.015$, Mann-Whitney-U).

Discussion

Findings from this study indicate that asthma control improved in the self-management group in terms of a higher number of successfully treated weeks and fewer limited activity days. There were no major changes in the lung function parameters. Based on initial levels of pre- and post bronchodilator FEV₁, the observed reversibility and initial dosage of inhaled steroids, included patients were a representative sample of mildly to moderately severe asthmatics^{5;18,27}. In the self-management group there was a slight improvement in asthma specific quality of life with a clinically relevant improvement in the emotions domain, indicating that patients in the self-management group felt less worried or insecure about the influence of their asthma on daily life. GPs did not diagnose more exacerbations, but the number of oral prednisolone courses was higher in the guided self-management group.

Thus far there are few randomised controlled trials to the effects of guided self-management programs in family medicine. As in our study most of these studies show limited reductions in symptoms or improvements in lung function and quality of life. Hoskins et al showed reductions in morbidity in terms of hospital admission, (emergency) consultations, oral steroid courses and emergency nebulisations. But due to possible selection bias superiority of self-management plans could not be proven²⁸. Their results suggest that improvements in clinical and morbidity parameters are indeed less likely to occur in mild asthmatics. This was also concluded by Jones et al, but they may have failed to show results due to the small number of subjects²⁹. On the other hand neither of these studies found that self-management caused unwanted loss of asthma control or increased morbidity. In our study we observed a significantly higher number of patients requiring one or more courses of oral steroids in the self-management group. Based on instructions in the self treatment plan patients could start an oral course of prednisolone independently,

so patients routinely were prescribed one prednisolone course at the third educational session. As there are strong indications that GPs accidentally recorded these prescriptions as true oral prednisolone courses overregistration may have occurred. An other explanation for the higher number of prednisolone courses may be the higher number of patients with an asthma attack in the previous six months and the higher number of patients requiring pre-treatment at the start of the study in the self-management group. This may indicate that asthma control in the self-management group initially was worse than in the usual care group. This is also reflected in a lower baseline quality of life. During the study changes in post BD FEV₁, FEV₁ reversibility and PC₂₀ did not differ in both groups. In the light of these findings the higher number of oral steroid courses in the self-management group can be attributed to a baseline between-group difference in asthma control. Additionally the use of oral steroids can be biased by instructions in the guided self-management program. Subjects in the self-management group were explicitly instructed about when to take oral courses of prednisolone. In this light the increased number of prescriptions may indicate either overtreatment or the self-treatment instructions worked as planned. In instances with more severe loss of asthma control adequate treatment was initiated without unnecessary delay, which is consistent with the increased number of successfully treated weeks and the lower number of lost-activity days.

The number of successfully treated weeks is an indicator of the burden of asthma as perceived by patients. It is based on perceived changes in dyspnea instead of the perceived levels of dyspnea. Patients constantly experiencing the same high levels of dyspnea may thus have a relatively high number of successfully treated weeks.

Presuming that the pre treatment phase did result in the highest achievable level of asthma control, constantly high symptom levels only are an indicator of experienced asthma severity, not asthma control. Subjects with increased weekly variations in perceived dyspnea levels will consequently have a lower number of successfully treated weeks. Accordingly the increased number of successfully treated weeks in the self-management group suggests less loss of asthma control in this group.

Observed changes in quality of life were statistically significantly different in favour of the self-management group. The magnitude of these gains however is limited. At

baseline quality of life was high in both groups. This may have left little room for improvement. The finding that the observed baseline differences in quality of life scores completely disappeared after 24 months may indicate that quality of life has been maximised in both groups.

Based upon our findings we conclude that self-management of asthma is at least equally effective as asthma treatment usually provided in Dutch primary care. Self-management of asthma provides a safe basis for intermittent therapy with inhaled corticosteroids and lowers the burden of illness as perceived by patients.

References

1. Barnes PJ, Jonsson B, Klim JB. The costs of asthma. *Eur Respir J* 1996;9:636-42.
2. Bone RC. Goals of asthma management. A step-care approach [see comments]. *Chest* 1996;109:1056-65.
3. British Thoracic Society. Guidelines on the management of asthma. *Thorax* 1993;48:S1-S24.
4. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997;52:S1-S21.
5. anonymous. Global strategy for asthma management and prevention NHLBI/WHO workshop report. 95-3659. 1995. National heart, lung and blood institute.
6. Cochrane GM. Compliance and outcomes in patients with asthma. *DRUGS* 1996;52(Supplement):12-9.
7. Bosley CM, Parry DT, Cochrane GM. Patient compliance with inhaled medication: does combining beta- agonists with corticosteroids improve compliance? [see comments]. *Eur Respir J* 1994;7:504-9.
8. Yeung M, O'Connor SA, Parry DT, Cochrane GM. Compliance with prescribed drug therapy in asthma. *Respir Med* 1994;88:31-5.
9. Dompeling E, van Grunsven PM, van Schayck CP, Folgering H, Molema J, van Weel C. Treatment with inhaled steroids in asthma and chronic bronchitis: long-term compliance and inhaler technique. *Fam Pract* 1992;9:161-6.
10. Horn CR, Clark TJ, Cochrane GM. Compliance with inhaled therapy and morbidity from asthma. *Respir Med* 1990;84:67-70.
11. Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health related quality of life in asthma: development of a questionnaire for use in clinical trials. *Thorax* 1992;47:76-83.
12. Juniper EF, Guyatt GH, Ferrie PJ, Griffith LE. Measuring quality of life in asthma. *Am Rev Respir Dis* 1993;147:832-8.
13. van Schayck CP, van den Broek PJ, den Otter JJ, van Herwaarden CL, Molema J, van Weel C. Periodic treatment regimens with inhaled steroids in asthma or chronic obstructive pulmonary disease. Is it possible? *JAMA* 1995;274:161-4.

14. van Grunsven PM, Dompeling E, van Schayck CP, Molema J, Folgering H, van Weel C. Treatment of mild asthma with inhaled corticosteroids: Is discontinuation of therapy possible? *Fam Med* 1996;28:46-51.
15. Thoonen BPA, Schermer TRJ, Akkermans RP, den Otter JJ, Grol RP, van Schayck CP. Willingness of patients to perform self-management of asthma and the role of inhaled steroids. *Scan J Prim Health Care* 2002;20:60-4.
16. Thoonen BPA, Jones KP, van Rooij HA, van den Hout AC, Smeele I, Grol R et al. Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view. *Fam Pract* 1999;16:117-22.
17. Abdulwadud OA, Abramson MJ, Light L, Thien FC, Walters EH. Comparison of patients with asthma managed in general practice and in a hospital clinic [see comments]. *Med J Aust* 1999;171:72-5.
18. Geijer RMM, van Hensbergen W, Bottema BJAM, van Schayck CP, Sachs APE, Smeele IJM et al. NHG-Standaard astma bij volwassenen: behandeling. *Huisarts Wet* 1997;40:443-54.
19. van der Waart MAC, Dekker FW, Nijhoff S, Thiadens HA, van Weel C, Helder M et al. NHG-standaard CARA bij volwassenen: behandeling [NHG Guideline on CNSLD in adults: treatment]. *Huisarts Wet* 1992;35:437-43.
20. Thoonen BPA, Schermer TRJ, Jansen M, Smeele I, Jacobs JE, Grol R et al. Asthma education tailored to individual patient needs can optimise partnerships in asthma self-management. *Patient Educ Couns* 2002;47:355-60.
21. Sterk PJ, Fabbri LM, Quanjer PH, Cockcroft DW, O'Byrne PM, Anderson SD, Juniper EF, Malo JL. Airway responsiveness. Standardized challenge testing with pharmacological, physical and sensitizing stimuli in adults. *Eur Resp J* 1993;6 Suppl. 16:53-83.
22. Bijl-Hofland ID, I, Folgering HT, van den HH, Cloosterman SG, van Weel C, Donkers JM et al. Perception of bronchoconstriction in asthma patients measured during histamine challenge test. *Eur Respir J* 1999;14:1049-54.
23. Lipworth BJ. Pharmacokinetics of inhaled drugs [see comments]. *Br J Clin Pharmacol* 1996;42:697-705.
24. van der Palen J, Klein JJ. Self-management of asthma by adults. Development and evaluation of a program with an emphasis on self-treatment of exacerbations [thesis]. 1998. Medisch Spectrum Twente.

25. Diggle PJ, Liang KY, Zeger SL. Analysis of longitudinal data. Oxford (UK): Oxford University Press, 1994.
26. Littell RC, Milliken GA, Stroup WW, Wolfinger RD. SAS system for mixed models. Cary, NC: SAS Institute Inc., 1996.
27. Gejjer RMM, Thiadens HA, Smeele IJM, van der Zwan AAC, Sachs APE, Bottema BJAM et al. NHG-Standaard COPD en astma bij volwassenen: diagnostiek. Huisarts Wet 1997;40:416-29.
28. Hoskins G, Neville RG, Smith B, Clark RA. Do self-management plans reduce morbidity in patients with asthma? Br J Gen Pract 1996;46:169-71.
29. Jones KP, Mullee MA, Middleton M, Chapman E, Holgate ST. Peak flow based asthma self-management: a randomised controlled study in general practice. British Thoracic Society Research Committee. Thorax 1995;50:851-7.

A randomised-controlled economic evaluation of asthma self-management in primary health care

Tjard R Schermer¹ MSc, Bart P Thoonen¹ MD, Guido van den Boom¹ PhD, Reinier P Akkermans¹ MSc, Richard P Grol² PhD, Hans T Folgering³ MD, PhD, Chris van Weel¹ MD, PhD, Constant P van Schayck^{1,4} PhD

¹ Department of General Practice / Family Medicine, University Medical Centre St Radboud, Nijmegen, the Netherlands;

² Centre for Quality of Care Research, University Medical Centre St Radboud, Nijmegen, and University of Maastricht, the Netherlands;

³ University Lungcentre Dekkerswald, University Medical Centre St Radboud, Nijmegen, the Netherlands;

⁴ At present: Department of General Practice / Family Medicine, University of Maastricht, the Netherlands

Revised submission: Am J Respir Crit Care Med

Abstract

In this randomised controlled economic evaluation we compared guided asthma self-management with usual asthma care according to guidelines for Dutch family physicians. 19 family practices were randomised, 193 stable adult asthmatics (98 self-management, 95 usual care) included and followed for 2 years. We hypothesised that introducing self-management would not compromise asthma control and cost would be equal or lower than in usual care. Patient-specific cost data were collected, preference-based utilities assessed, and incremental cost per quality-adjusted life year (QALY) and successfully treated week gained calculated. Self-management patients gained 0.039 QALYs (95%CI 0.003; 0.075) and experienced 81 (95%CI 78; 84) successfully treated weeks in two years time; the corresponding figures for usual care were 0.024 (95%CI -0.022; 0.071) and 75 (95%CI 72; 78). Total cost was €1084 (95%CI 938; 1228) for self-management and €1097 (95%CI 933; 1260) for usual care. Self-management patients consumed 1680 (95%CI 1538; 1822) puffs budesonide, usual care patients 1897 (95%CI 1679; 2115). Mean productivity cost due to limited activity days was €213 lower in self-management patients. When all costs were included, self-management was cost-effective on all outcomes. The probability that self-management was cost-effective relative to usual care in terms of QALYs was 52%. We conclude that guided self-management is a safe and cost-effective alternative approach compared to asthma treatment usually provided in Dutch primary care.

Introduction

Asthma is a chronic respiratory disease affecting people of all ages. In western countries, 4 to 6% of the adult population have a physician-confirmed diagnosis of bronchial asthma^{1,2}. Compliance with prophylactic inhaled corticosteroid treatment is poor in many asthma patients, thus limiting its effectiveness^{3,4}. Because the cost of asthma for society are largely due to the consequences of uncontrolled disease, it is presumed that the cost could be significantly reduced if disease control is improved⁵. Using a comprehensive approach generally consisting of education and training, written action plans and periodic supervision, health professionals may try to improve knowledge, practical skills, decision-making responsibility and, ultimately, disease

control in their asthma patients^{6;7}. A recent systematic review including twenty-three trials concluded that self-management programs are able to improve health outcomes in adult asthma if they include self-monitoring and are accompanied with written action plans and regular medical professional review⁸. However, the trials included in this meta-analysis have been conducted mainly in selected (secondary care) patients.

When competing for scarce health care resources it is not sufficient to determine the effects of asthma self-management programs solely in terms of health outcomes. It is also important to analyse whether the cost of introducing self-management outweigh the -potential- subsequent savings in health care utilisation and productivity ('indirect') costs, the latter resulting from fewer days of limited activities and incapacity for work⁹. If the savings do not outweigh the investments, it is essential to assess whether the additional –or incremental– cost of a self-management program can be justified by the health gains.

Meanwhile, several asthma guidelines recommend self-management^{10;11} and health professionals and asthma patients themselves seem to appreciate the contemporary approach¹²⁻¹⁴. A number of economic evaluations on asthma education and self-management have been published¹⁵⁻²⁶ but most authors have confined themselves to separate descriptions of costs and health effects without directly assessing their relationship by calculating summary ratios. Essential methodological shortcomings were the absence of a control group receiving an appropriate comparator treatment and a too short duration of follow-up. None of the published economic studies included instruments to assess preference-based utilities (e.g., quality-adjusted life years (QALYs) or similar universal outcome measures) as is currently recommended for all economic evaluations^{27;28}. Moreover, only a part of the studies used written action plans, which seems to be a prerequisite for a successful treatment result⁸. This paper reports a state-of-the-art economic evaluation of a guided self-management program for adult asthma patients treated in Dutch primary care. We compared the self-management program with the 'best' generally available medical treatment for asthma ('usual care') according to asthma treatment guidelines for family physicians^{29;30}. Beforehand, we did not expect substantial differences in health outcomes because medical care for asthma patients is already of a high standard in

the Netherlands, with asthma-related hospital admissions and deaths almost becoming rare events³¹. Therefore, the main objective of this evaluation was to investigate whether a family practice based self-management program for adult asthmatics provides an efficient treatment alternative in terms of health care utilisation and absence from work, without asthma control being compromised.

Methods

Study design

The study was a randomised controlled parallel group multi-centre clinical trial. Nineteen (19) Dutch family practices (49 family physicians) were randomly allocated to guided self-management or usual care. Randomisation was stratified on type of practice, number of asthmatics initially identified from the practice records and use of a computerised prescription system. Duration of follow-up was two years per patient. Self-management and usual care were fully pursued by the family physicians, no other health professionals were involved. The study protocol was approved by the medical ethical committee of the University Medical Centre St Radboud. Patients gave written informed consent before study entry. The first subject entered the study in March 1996, the last subject completed the study in June 1999.

Participants

The 49 family physicians involved in the study selected asthmatic subjects aged 16-60 years who were to be treated with inhaled steroids according to national guidelines^{30;31}. Identification of subjects was based on the following information sources: problem list coding (International Classification of Primary Care (ICPC): R96); prescription of inhaled steroids or bronchodilators from practice or pharmacy records; and the annual influenza vaccination campaign list. Subjects willing to participate were included if (1) PC_{20} (provocative dose of histamine causing a 20% drop in FEV_1) < 8 mg/ml and/or reversibility of FEV_1 $> 9\%$ of the predicted value after 800 micrograms salbutamol aerosol administered by spacer; (2) smoking history < 15 packyears; (3) not currently treated by a chest physician; (4) able to communicate in

the Dutch language. Eligible patients with an initial FEV_1 <80% of the predicted value were pre-treated with budesonide 800 micrograms b.i.d. during 6 weeks.

Guided self-management and usual care

All participants were prescribed budesonide administered by multi-dose dry powder inhaler (Pulmicort Turbuhaler®, 200*200 microgram, Astra Zeneca BV, Zoetermeer, the Netherlands) by one of the investigators (BT). Participants received new budesonide inhalers and handed-in used inhalers during half-yearly visits to the pulmonary function laboratory. The patient's own family physician was responsible for regulating the dosage scheme at study entry. Family physicians were not restricted in prescribing non-steroid lung medication in either group, apart from cromoglycates and nedocromil being prohibited during the trial. Bronchodilators were preferably prescribed on an as-needed basis, if necessary at all.

Self-management patients received education and training of skills on an individual basis from their family physician. Training consisted of four visits to the practice scheduled within a period of 3 months. Subsequent control visits for the remaining follow-up period of 21 months were recommended, but it was left to the initiative of the family physician and patient if and when these visits took place. Training tools consisted of (1) a detailed manual for the physicians describing the educational topics to be discussed during the consecutive training sessions and instructions on how to teach patients self-management skills (i.e. peak flow measurement, proper inhalation technique, completing the self-management diary, application of self-treatment guidelines); (2) checklists for patients and physicians to assess and record specific information needs of patients; (3) two booklets of the Dutch Asthma Foundation, one containing general information about asthma, the other information about asthma medication; (4) diaries containing self-treatment guidelines, also used for data collection. Self-management patients were equipped with a portable peak flow meter (Asmaplan+, Vitalograph Ltd., Buckingham, UK) and instructed to measure morning and evening peak expiratory flow rates once a week and record the best of three attempts in their diary. Self-treatment guidelines were based on peak flow values and severity of respiratory symptoms (figure 7.1). Detailed information on the exact contents of the education program and self-treatment

Figure 7.1: Summary of step-up and step-down instructions for self-management patients regarding the use of budesonide.

Step-up instructions

- *PEFR[†] deteriorates <80% PEFR \geq 60% of PBV for 3 consecutive days:*
double* budesonide dosage
in case of insufficient response within three weeks: again double* budesonide dosage
- *PEFR[†] deteriorates <60% PEFR \geq 40% of PBV for 3 consecutive days:*
increase budesonide dosage to 800 micrograms b.i.d.
in case of insufficient response within two days: start course of oral prednisolone
and contact your family physician
- *PEFR[†] deteriorates <40% of PBV for 3 consecutive days:*
immediately contact your family physician

Step-down instructions

- *PEFR[†] improves to \geq 40% PEFR <60% of PBV:*
continue the current budesonide dosage until your PEFR is >60% of PBV
- *PEFR[†] improves to \geq 60% PEFR <80% PBV:*
continue the current budesonide dosage until your PEFR is >80% of PBV
- *PEFR[†] improves to \geq 80% of PBV:*
halve budesonide dosage when PEFR \geq 80% for a period of two weeks

* If no budesonide was used at the time of deteriorating peak flow, the patient should commence with the lowest dose (200 microgram b.i.d.). Patients were not allowed to double their dosage of budesonide anymore once the maximum dosage of 800 micrograms b.i.d. had been reached

† either morning or evening value

PEFR: peak expiratory flow rate

PBV: personal best value

guidelines have been published elsewhere³³. Usual care physicians were instructed to adhere to the asthma treatment guidelines issued by the Dutch College of Family Physicians in 1992²⁹ and to the revised guidelines issued in 1997³⁰. Usual care patients did not receive peak flow meters, nor were they instructed on how to adjust their dosage of budesonide.

Clinical effectiveness

Clinical effectiveness was evaluated on the basis of asthma control parameters and quality of life. Asthma control was expressed as the number of successfully treated weeks in two years follow-up, changes in post-bronchodilator FEV₁ (forced expiratory volume in one second), changes in FEV₁ reversibility as percentage of predicted value, and changes in PC₂₀-histamine³³. Asthma-specific quality of life was assessed using the interview-administered 32-question Asthma Quality of Life (AQLQ) questionnaire³⁴. This instrument assesses four domains: (1) asthma symptoms; (2) limitation of activity; (3) emotional dysfunction and (4) responses to environmental stimuli, respectively. An overall score as well as separate domain scores were calculated.

Economic evaluation: data collection and resource valuation

A societal perspective was adopted for the economic evaluation. Patient specific resource use was measured in natural units if possible. Resource use was valued in monetary terms by multiplying the units consumed with the cost per unit. Three major cost categories were distinguished: program implementation, direct health care, and productivity ('indirect') costs. The specific cost components can be read from tables 7.3 and 7.4.

Data regarding bronchodilators and other prescribed non-steroid asthma medication, over-the-counter medication and limited activity days were extracted from the diary cards. A limited activity day was defined as any day on which a patient could not perform his or her usual (paid or unpaid) daily activities. Consumption of budesonide was assessed by counting the remaining puffs in the inhalers returned and by registration on the diary cards. We considered the puff counts as the most reliable source of information for estimating budesonide consumption³⁶. Patient out-of-pocket

cost on house dust mite allergen avoidance measures and smoking cessation attempts were assessed retrospectively by an *ad hoc* questionnaire. Family physicians reported details of asthma-related consultations, medication prescriptions, influenza vaccinations, referrals and diagnostic procedures on study report forms. Completeness of consultation data was verified after a patient had completed study participation.

The first-choice source for resource unit valuation was the sum charged by family physicians to privately insured patients (including V.A.T. and a mark-up for administrative expenses). Secondary sources were annually updated drugs and diagnostic indexes^{35,36} and recent recommendations regarding cost analysis³⁷ (all issued by the Dutch College of Health Insurance), study expense accounts and patient questionnaires. The human capital approach²⁸ was adopted to value limited activity days. An individual hourly wage based on the gross monthly income and the number of hours of disbursed work was calculated for all participants in paid employment. The resultant average gross hourly wage (€9.53) was subsequently used to convert all limited activity days (eight hour workday) into monetary terms, regardless of the employment status or income of individual participants. All resources used were valued in Dutch guilders and converted to Euros (€). For conversion to US\$, costs in € should be multiplied by a factor 0.912, based on the 2000 Purchasing Power Parities as issued by the Organisation for Economic Co-operation and Development (www.oecd.org). Purchasing Power Parities are the rates of currency conversion that equalise the purchasing power of different currencies, thus eliminating differences in price levels between countries. Costs nor effects were discounted for time preferences.

Cost-effectiveness analysis: outcome measures

We performed a 'Reference Case' cost-effectiveness analysis as recommended by Gold *et al*²⁷ as well as secondary cost-effectiveness analyses. With the term Reference Case we refer to an analysis in which the direct health care cost, program implementation cost and productivity cost of patients are included. Outcome for the Reference Case analysis was defined in terms of quality-adjusted life-years (QALYs). In order to calculate QALYs, preference based utilities were assessed at baseline and

half-yearly at the lung function laboratory. An interval rating scale ranging from 0 to 1 was used for this purpose, 0 being equal to death and 1 being equal to perfect health³⁸. Participants first marked a standardised (hypothetical) reference health state on the rating scale and subsequently their own perceived health state. The number of successfully treated weeks served as the main outcome for secondary cost-effectiveness analyses⁹. Successfully treated weeks were defined on the basis of recorded scores for shortness-of-breath in the diaries (modified Borg interval scale, scoring 0 = no shortness of breath; 10 = maximal shortness of breath)³⁹. Any given week with a score higher than the individuals' median score over the total follow-up was considered as an unacceptable low level of control of asthma symptoms and therefore counted as *un*successful. Subtracting this figure from the individual's total number of recorded weeks resulted in the proportion of weeks being treated successfully, which was eventually standardised to the number of successfully treated weeks per two years (104 weeks). Next to successfully treated weeks, the number of patients with a minimal clinically important difference (MCID) in quality of life between the baseline and final visit was studied as a secondary outcome. MCID was defined as a within-subject improvement of 0.5 unit on the overall AQLQ or domain scores³⁴.

Statistical analysis

Patients were included in the intention-to-treat analysis if they had been present at the first follow-up visit at the pulmonary function laboratory after 6 months. Although distributions of resource units were skewed to the right for most cost components, arithmetic means and *t* test based ninety-five percent confidence intervals (95% CIs) were calculated to compare self-management and usual care groups⁴¹. Within-group cost differences between the first and second study year were analysed by paired, between-group differences by unpaired *t* test. QALYs were determined by calculating the area-under-the-curve (time*rating scale score) for each individual participant. Mean costs and effects were multiplied by a constant of 100 in order to standardise for inequalities of group sizes. Because of that, cost-effectiveness results reflect a situation in which two groups of one-hundred patients each would receive either self-management or usual care. Consequently, the cost-effectiveness ratios of the AQLQ

data should be interpreted as the incremental cost or net savings to improve quality of life in one patient. A treatment was qualified to be 'dominant' when this particular treatment was both more effective and less costly than the alternative²⁷. Secondary analyses were performed by calculating cost-effectiveness ratios with exclusion of the productivity cost.

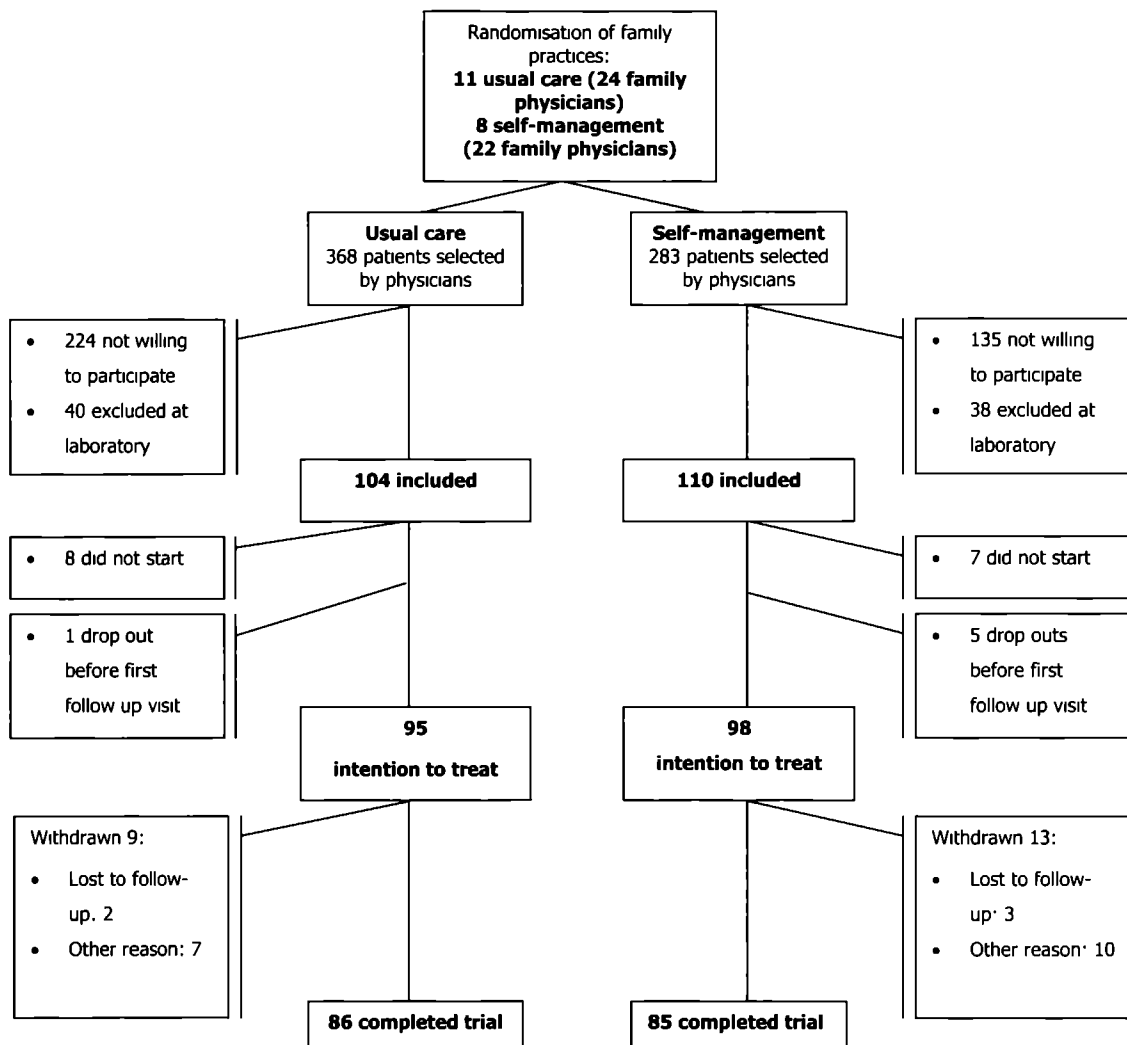
The *SAS* statistical software package (SAS Institute Inc., Release 6.12 for Windows, Cary, NC, US) was used for statistical analyses. With regards to the incremental cost per successfully treated week, a 95% CI was determined based on Fiellers theorem⁴³. In order to express uncertainty in the estimated incremental cost per QALY, *Data for Health Care* software (Data Pro, Treeage Inc., Williamstown, MA, US) was used to generate graphical representations of the cost-effectiveness plane and accompanying two-dimensional 90% and 95% confidence intervals. This was done using Monte Carlo simulation by drawing 1000 random samples with size $n=100$ each from the actual cost and QALY study data from the two comparator groups. Each point in the resulting scatterplot represents the incremental cost-effectiveness ratio of one iteration of the Monte Carlo simulation. A diagonal line intersecting the origin of the plot simplifies identification of points for which the incremental cost-effectiveness ratio of self-management versus usual care is less than, or equal to, a *a priori* specified societal 'willingness-to-pay/limit'⁴⁴ (λ) to gain one additional QALY. Arbitrarily, λ was set on €22,500. A graphical representation ('acceptability curve') of the probability that a particular intervention is cost-effective over a range of increasing values for λ was generated⁴⁵. This bayesian approach of the stochastic analysis provides information relevant to health care decision making.

Results

Study population and clinical effects

Ninety-eight (98) self-management and 95 usual care patients were included in the intention-to-treat analyses (figure 7.2). Treatment groups did not differ on general or clinical characteristics at baseline, apart from a higher proportion of patients reporting a recent episode of aggravated asthma symptoms and lower AQLQ scores in the self-management group (table 7.1). Fourteen (14) self-management patients

Figure 7.2: Flow chart of recruitment and drop out of study participants.



and 16 usual care patients did not use bronchodilator medication during the study. Twelve (12) self-management and 5 usual care patients used a long-acting beta2-agonist, theophyllines were used by 3 self-management patients only. The course of the pre- and post-bronchodilator FEV₁ did not differ between groups, nor did FEV₁

reversibility or PC₂₀³³. The mean number of successfully treated weeks in two years time was 81 (95% CI 78; 84) for self-management and 75 (95% CI 72; 78) for usual care (table 7.2). This corresponds with a statistically significant gain of 6 successfully treated weeks in two years in favour of self-management. In the self-management group 17% (95% CI 10; 24) more participants showed a MCID on the AQLQ emotions domain compared to usual care. No statistically significant differences were observed for the activities, environmental and symptoms domains, or the total AQLQ score.

Cost analysis

The total implementation cost of the self-management program amounted to €189 (95% CI 179; 199) per patient (table 7.3). Time invested by family physicians and purchase of peak flow meters constituted the major part of the implementation cost (60% and 16%, respectively). Mean budesonide usage was 1680 puffs (95% CI 1538; 1822) or €414 for self-management and 1897 puffs (95% CI 1679; 2115) or €467 for usual care, indicating a saving of 217 puffs or €53 per patient during the 2-year follow-up (table 7.4). Converted to the level of budesonide inhalers, 0.5 inhalers per year were saved by self-management patients. Cost of short-acting bronchodilators were significantly lower for self-management, but this difference was largely compensated by the higher cost of long-acting beta₂-agonists and theophyllines in this same group. During the study, 30 (31%) self-management and 10 (11%) usual care patients took domestic house dust mite avoidance measures (Relative Risk = 1.7, 95% CI 1.3; 2.2). Consequently, mean cost of domestic house dust mite allergen avoidance measures were significantly higher among self-management patients (€193 *versus* €109 for usual care, $p=0.0015$). Although the cost of influenza vaccinations comprised only a marginal proportion of the total direct cost, there were significantly more vaccinations in the self-management group (table 7.4): 46 (47%) self-management and 27 (28%) usual care patients received at least one influenza vaccination during follow-up (Relative Risk = 1.5, 95% CI 1.1; 1.9). There were more referrals to chest physicians among self-management than among usual care patients: 9 (4.6%) and 1 (0.6%), respectively ($p=0.011$). No asthma-related emergency unit visits or hospital admissions were reported.

Table 7.1. Baseline characteristics of the study population by treatment group.
Figures are means (SD) unless stated otherwise

	Self-management (n = 98)	Usual care (n = 95)	p value
General characteristics			
Age (years)	39.6 (11.2)	39.3 (12.0)	0.859
Sex (male/female)	34/64	40/56	0.394
Employment status			
Student (%)	5	4	
Full-time or part-time job (%)	66	66	
Unemployed or retired (%)	29	30	0.953
Smoking status			
Never smokers	45 (46%)	55 (56%)	
Former smokers	31 (32%)	21 (22%)	
Current smokers	22 (22%)	21 (22%)	0.254
Packyears (number)	5.8 (4.5)	5.7 (4.5)	0.881
Clinical characteristics			
Duration of asthma* (years)	21.0 (16.5)	18.1 (14.3)	0.232
Subjects with asthma attack(s) in previous 6 months	47 (48%)	30 (32%)	0.017
Allergy (number of positive skin prick tests)†			
0	19 (23%)	20 (26%)	
1-3	37 (44%)	29 (38%)	
≥4	28 (33%)	27 (36%)	0.735
Lung function parameters			
FEV ₁ post-BD % of predicted value	90.0 (12.1)	92.6 (12.9)	0.135
Median FEV ₁ reversibility‡ (%)	5.0 (IQR 8.6)	5.4 (IQR 6.8)	0.930
PC ₂₀ geometric mean	1.20	0.97	0.442
Utilities and quality of life			
Utilities			
Median 'Own health state'	0.80 (IQR 0.15)	0.80 (IQR 0.16)	0.668
Median 'Reference health state'	0.40 (IQR 0.30)	0.40 (IQR 0.20)	0.380
Quality of life			
Overall AQLQ score	5.4 (0.87)	5.7 (0.77)	0.013
AQLQ activities domain	5.3 (1.03)	5.6 (0.77)	0.015
AQLQ emotions domain	5.8 (1.01)	6.2 (0.76)	0.002
AQLQ symptoms domain	5.3 (1.03)	5.6 (0.90)	0.074
AQLQ environment domain	5.3 (1.10)	5.5 (1.1)	0.165

* missing in 17 self-management and 14 usual care patients

† missing in 14 self-management and 19 usual care patients

‡ difference between FEV₁ % predicted before and after bronchodilator

AQLQ Asthma Quality of Life Questionnaire

FEV₁ forced expiratory volume in one second

FVC forced vital capacity

IQR inter quartile range

Table 7.2. Average and incremental effects of self-management and usual care in adult asthmatics.

Results of the Reference Case analysis are printed in **bold** figures. Increments are standardised to 100 subjects per group treated for two years.

	Self-management	Usual care	
Outcome	Average effect		Incremental [†] effect of self-management in 100 subjects treated for two years
QALYs (95% CI)	0.039 (0.003, 0.075)	0.024 (-0.022, 0.071)	+1.5 (-1.4, 4.4)
Number of successfully treated weeks (95% CI)	81 (78, 84)	75 (72, 78)	+600 (230, 970)
Proportion of subjects with MCID:			
AQLQ total score [†] (95% CI)	39 (29, 48)	29 (20, 38)	+10 (-3, 23)
AQLQ emotions domain [†] (95% CI)	42 (32, 51)	25 (16, 33)	+17 (10, 24)
AQLQ activities domain [†] (95% CI)	52 (42, 62)	39 (30, 49)	+13 (-1, 27)
AQLQ symptoms domain [†] (95% CI)	35 (26, 45)	28 (19, 37)	+7 (-6, 20)
AQLQ environment domain [†] (95% CI)	42 (32, 51)	39 (30, 49)	+3 (-11, 17)

* self-management minus usual care

† final AQLQ measurement was missing in 2 self-management and 6 usual care patients

AQLQ: Asthma Quality of Life Questionnaire

MCID: minimal clinically important difference

QALY: quality adjusted life year

Table 7.3. Breakdown of the implementation cost of the self-management program for 98 adult asthmatics treated for two years in eight family practices

Component of cost	Source for unit valuation	Unit	Number of units	Cost/unit (€)	Total cost (€)
Preparation					
Pre-study training and instruction of family physicians	[a]	hours	23	73.53	1,691
Application of self-management program					
Educational and self-management aids	[b]	set*	98	14.25	1,396
Peak flow meters	[b]	meter	98	29.61	2,902
Education sessions:					
Family physician time	[a]	hours	151	73.53	11,075
Patient time	[c]	hours	151	9.53 [†]	1,436
Total implementation cost					18,500
Average implementation cost per patient (95% CI)					189 (179, 199)

* set: all materials necessary to educate and train one patient, i.e. information brochures, self-management diaries and information feedback forms

† based on the average gross hourly wage of all employed participants

Sources used for unit valuation

- [a] Guidebook for Cost Investigation (Dutch College of Health Insurance, reference 39)
- [b] retail prices (index year 2000)
- [c] study-specific inquiry by questionnaire

Mean direct health care cost aggregated to €809 (95% CI 683; 934) for self-management and €798 (95% CI 682; 914) for usual care (table 7.4).

Seventy-nine percent (79%) of self-management and 62% of usual care patients reported one or more limited activity days at some point during follow-up. The mean number of limited activity days was 1.9 (95% CI 0.7; 3.2) for self-management and 6.0 (95% CI 2.6; 9.4) for usual care, corresponding with mean productivity cost of €144 and €462, respectively. However, closer examination of the productivity cost data identified two distinct outliers in the usual care group with productivity cost of

€10,831 (142 limited activity days) and €5,263 (69 limited activity days), respectively. One outlier had a period of several months with frequent but short episodes of sick leave due to asthma, the other a three-month episode of uninterrupted sick leave. In both cases, irritant exposure in the workplace explained the high productivity cost. Because of the clear work-related cause and the disproportionate impact of these two outliers on the average productivity cost in the usual care group, we decided to exclude subjects above the 98th percentile of the productivity cost distribution from the final cost calculations in both groups. This resulted in an average number of limited activity days of 1.2 (95% CI 0.5; 1.9) for self-management and 3.9 (2.5; 5.4) for usual care, corresponding with a €213 productivity cost saving for self-management (table 7.4). We consider the productivity cost without the outliers as the main results.

The sum of direct health care and implementation costs amounted to a difference of €199 (95% CI 70; 328) in favour of usual care (table 7.5). The between-group difference in the total cost of €13 was not statistically significant ($p=0.906$).

Analysing the cost for the first and second year separately showed that, as expected, the major part (91%) of the program implementation cost was spent during the first study year (figure 7.3). A significant reduction of the productivity cost from the first to the second year was observed for self-management ($p=0.036$) but not for usual care ($p=0.487$). During the second year the total cost per patient were €147 ($p=0.0013$) lower in the self-management group.

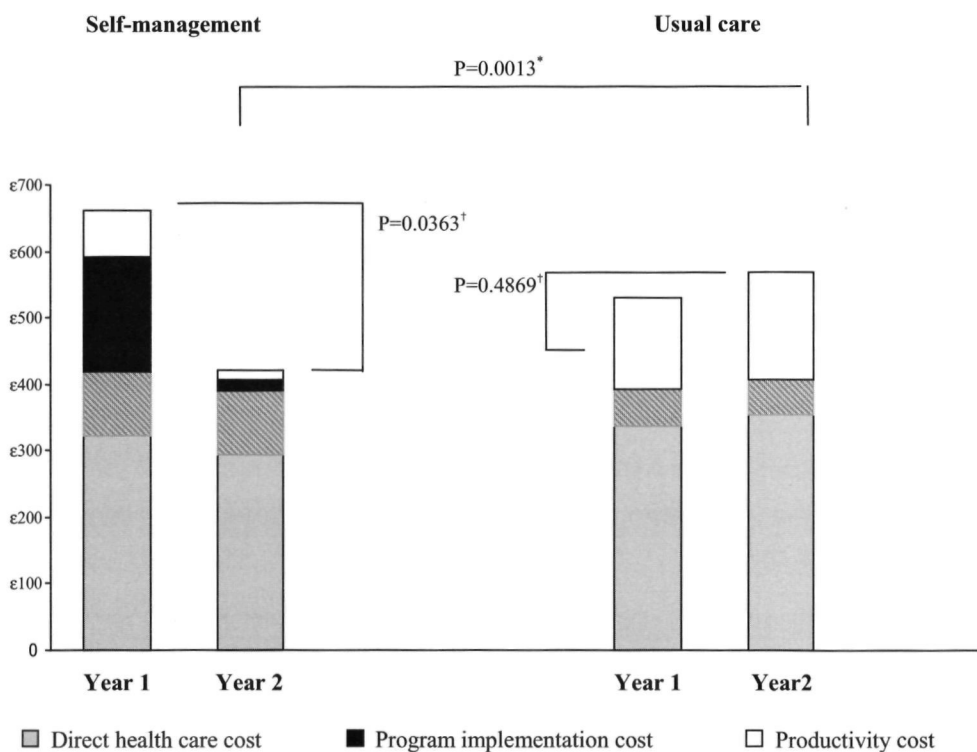
Reference Case cost-effectiveness analysis

The course of rating scale scores is given in figure 7.4. The mean number of QALYs gained during the two year follow-up was 0.039 (95% CI 0.003; 0.075) for self-management and 0.024 (95% CI -0.022; 0.071) for usual care (table 7.2). This would imply that in 100 patients with asthma, self-management is associated with a gain of 1.5 QALY (95 % CI -1.4; 4.4) relative to usual care. In terms of cost-effectiveness, self-management dominated usual care (table 7.6). Uncertainty around the incremental cost per QALY point estimate is depicted in figure 7.5. This scatterplot shows that the uncertainty around the cost-effectiveness estimate is large. In other words, the dominance of self-management cannot be firmly

established. This is supported by the cost-effectiveness acceptability curve (figure 7.6): regardless of the societal willingness-to-pay, the probability that self-management is cost-effective relative to usual care is approximately 52% when a prior probability of 50% is assumed.

Figure 7.3. Cost analysis for the first and second year of follow up of self-management and usual care patients.

The cross-hatched area in the grey section of each bar represents the patient out-of-pocket cost for domestic allergen avoidance measures.



* between-group difference in total cost for year 2 (unpaired t test)

† within-group difference in productivity cost between year 1 and year 2 (paired t test)

‡ within-group difference in indirect cost between year 1 and year 2 (paired t test)

Table 7.4. Mean and incremental program implementation, direct health care and productivity cost (€) of self-management and usual care per patient per two years. Figures in the black bars are the mean cost per cost category

Component of cost	Source for unit valuation	Self-management (n=98)			Usual care (n=95)			Incremental cost (€) ^{II}	
		Units	(95% CI)	Cost (€)	Units	(95% CI)	Cost (€)		
Program implementation cost									
(see table 2 for details)	[a b c]	98		189	0		0	+189	
Subtotal implementation cost:				189	(179, 199)		0	+189	
Direct health care cost									
Drugs and other interventions									
Budesonide (doses)	[d]	1680	(1538, 1822)	414	1897	(1679, 2115)	467	-53	
Short-acting bronchodilators (doses)	[d]	469	(347, 591)	84	796	(526, 1066)	141	-57	
Long-acting bronchodilators (doses)	[d]	67	(10, 124)	51	30	(-6, 66)	16	+35	
Theophylline (doses)	[d]	11	(-5, 26)	2	0		0	+2	
Prednisone (courses)	[d]	0.33	(0.19, 0.46)	3	0.22	(0.08 , 0.36)	2	+1	
Antibiotics (courses)	[d]	0.28	(0.11, 0.44)	1	0.40	(0.19, 0.61)	2	-1	
Other asthma medication*	[b d e]	N/A.		2	N/A.		6	-4	
Influenza vaccinations (number)	[d]	0.72	(0.55, 0.90)	5	0.38	(0.25, 0.51)	3	+2	
Physiotherapy (courses)	[a]	0.03	(0, 0.07)	4	0.01	(-0.01, 0.03)	1	+3	
Allergen avoidance measures [†]	[c]	N/A.		193	N/A.		109	+84	
Other resources									
Family physician consultations (number)	[a]	2.2	(1.6, 2.8)	37	2.4	(1.9, 2.9)	40	-3	
Chest physician consultations (number)	[a]	0.09	(0.03, 0.15)	5	0.01	(-0.01, 0.03)	1	+4	
Diagnostic procedures [‡]	[f]	N/A.		6	N/A.		6	0	
Emergency room visits (number)	-	0		0	0		0	0	
Hospital admissions (number)	-	0		0	0		0	0	
Subtotal direct cost:				809	(683, 934)		798	(682, 914)	+11
Productivity cost									
Limited activity days (days) [§]	[c]	1.2	(0.5, 1.9)	86	3.9	(2.5, 5.4)	299	-213	
Subtotal productivity cost:				86	(35, 136)		299	(191, 406)	-213
Total cost:				1084	(938, 1228)		1097	(933, 1260)	-13

* both prescribed and over-the-counter medication

† purchase of house dust mite impermeable mattress covers, smooth floors, special vacuum cleaners and air cleaning equipment

‡ cost of various pulmonary function and allergy tests, chest X-rays and sputum cultures

§ highest two patients were excluded in both groups (see text)

II self-management minus usual care

N/A. not applicable

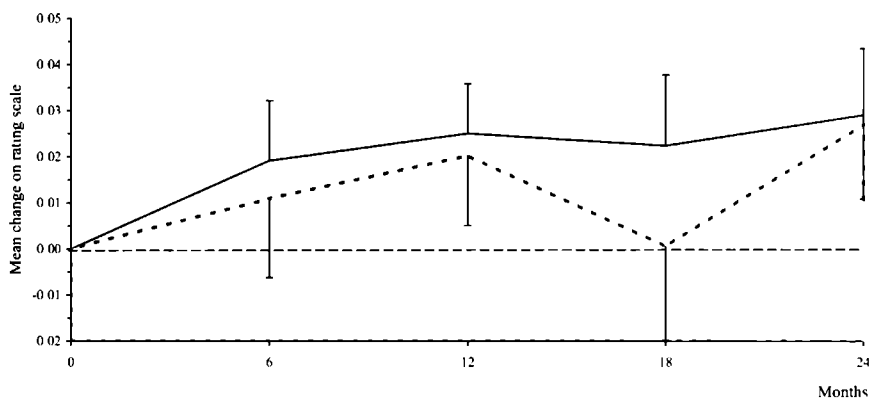
Sources used for unit valuation:

[a] Guidebook for Cost Investigation (Dutch College of Health Insurance, reference 39)

- [b] retail prices (index year 2000)
- [c] study-specific inquiry by questionnaire
- [d] sum charged by family physicians to privately insured patients, including administrative expenses
- [e] Pharmacotherapeutic Compass (Dutch College of Health Insurance, reference 37)
- [f] Diagnostic Compass (Dutch College of Health Insurance, reference 38)

Figure 7.4. Mean changes in rating scale scores for self-management and usual care groups adjusted for baseline level.

Vertical bars are standard errors. The grey area between the two lines represents the difference in QALYs between treatment groups*.



because not all participants had their laboratory visits scheduled at exactly 6,12, 18 and 24 months, the visual representation in this figure is an approximation of the exact sum of all individual QALYs as reported in the text and in table 2

— self-management
 ----- usual care

Secondary cost-effectiveness analyses

When productivity cost were excluded, the incremental cost per QALY of self-management relative to usual care was €13,267 (table 7.6). Self-management dominated usual care with regard to successfully treated weeks and the proportion of patients with a MCID in quality of life. Without the productivity cost, the incremental cost-effectiveness ratio was €33 (95% CI 4; 99) to gain one successfully treated week due to self-management (table 7.6). Cost-effectiveness ratios based on the cost per patient with a MCID in quality of life preponderantly pointed to self-

management as the dominant treatment, regardless of the inclusion or exclusion of productivity cost (table 7.6).

Table 7.5. Average and incremental cost (€) during two years of self-management and usual care in adult asthmatics.

Results of the Reference Case analysis are printed in **bold** figures. A plus sign indicates an expenditure due to the self-management program, a minus sign a saving

Cost components*			Self-management	Usual care	
Direct health care	Program implementation	Productivity	Average total cost (95% CI)		Incremental [†] cost of self-management per subject treated
■	■	■	1084 (938, 1228)	1097 (933, 1260)	-13 (-232, 206)
□	□	-	997 (871, 1124)	798 (681, 914)	+199 (70, 328)
□	-	□	894 (751, 1038)	1096 (933, 1260)	-202 (-420, 16)
□	-	-	809 (683, 934)	798 (681, 914)	+11 (-77, 99)

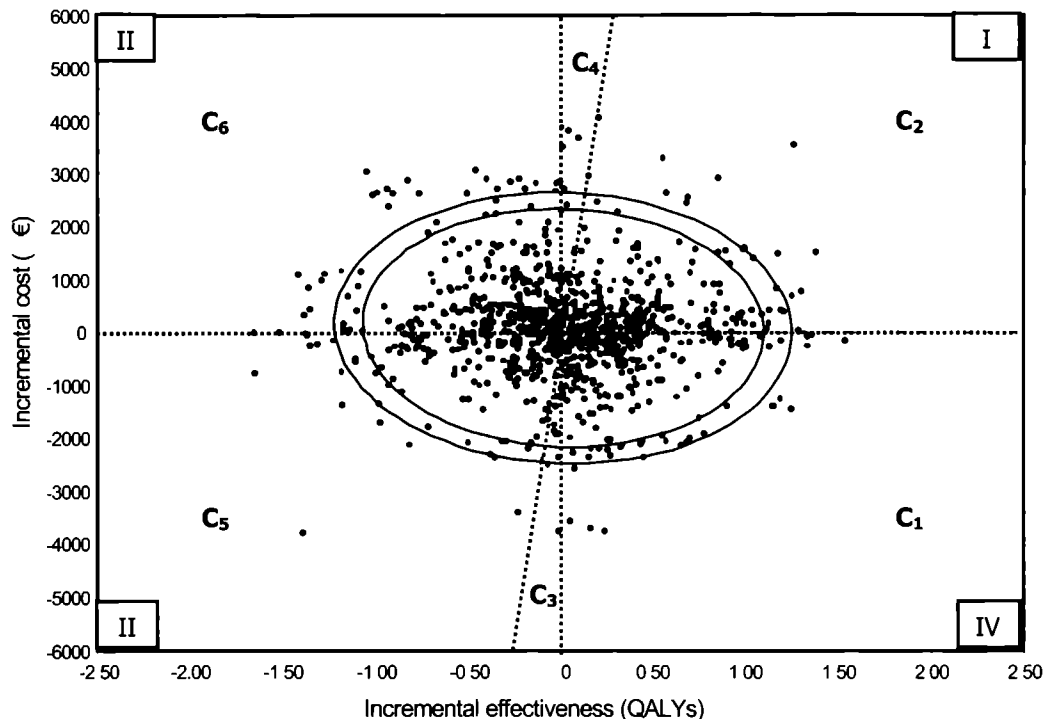
* ■ and □ indicate the cost components included in the calculations of mean costs

[†] self-management *minus* usual care

95% CI. ninety-five percent confidence interval

Figure 7.5. Scatterplot of 1000 modelled incremental cost per QALY estimates.

The table shows the proportion of iterations in the respective quadrants and compartments. Observations in compartments C₁, C₂ and C₃ indicate cost-effectiveness of self-management. The diagonal dashed line represents the societal willingness-to-pay (€22,500 per QALY, arbitrarily chosen). Inner and outer ellipses represent 95% and 90% confidence intervals, respectively).



Compartment	Quadrant	Incremental effectiveness	Incremental cost	Incremental cost-effectiveness ratio	Number of points	Percentage
C1	IV	>0	<0	Self-management dominant	264	26.4%
C2	I	>0	>0	<22,500	237	23.7%
C3	III	<0	<0	>22,500	16	1.6%
C4	I	>0	>0	>22,500	20	2.0%
C5	III	<0	<0	<22,500	190	19.0%
C6	II	<0	>0	Usual care dominant	273	27.3%

Table 7.6. Incremental cost-effectiveness ratios for asthma self-management relative to usual care during two years follow-up.

Cost are in Euros (€). Results of the Reference Case analysis are printed in **bold** figures.

	Productivity cost included (95% CI)	Productivity cost excluded (95% CI)
Incremental cost per QALY gained	Self-management dominant^{*,†}	13,267
Incremental cost per successfully treated week gained	Self-management dominant	33 (4, 99)
Observed incremental cost for one patient to experience a MCID, when 100 patients are treated:		
AQLQ [‡] total score	Self-management dominant	Self-management dominant
AQLQ [‡] emotions domain	Self-management dominant	Self-management dominant
AQLQ [‡] activities domain	Self-management dominant	Self-management dominant
AQLQ [‡] symptoms domain	Self-management dominant	1
AQLQ [‡] environment domain	Self-management dominant	328

* dominant: treatment both more effective and less costly than the alternative treatment

† uncertainty in the Reference Case cost per QALY estimate is depicted in figure 5

‡ final AQLQ measurement was missing in 2 self-management and 6 usual care patients

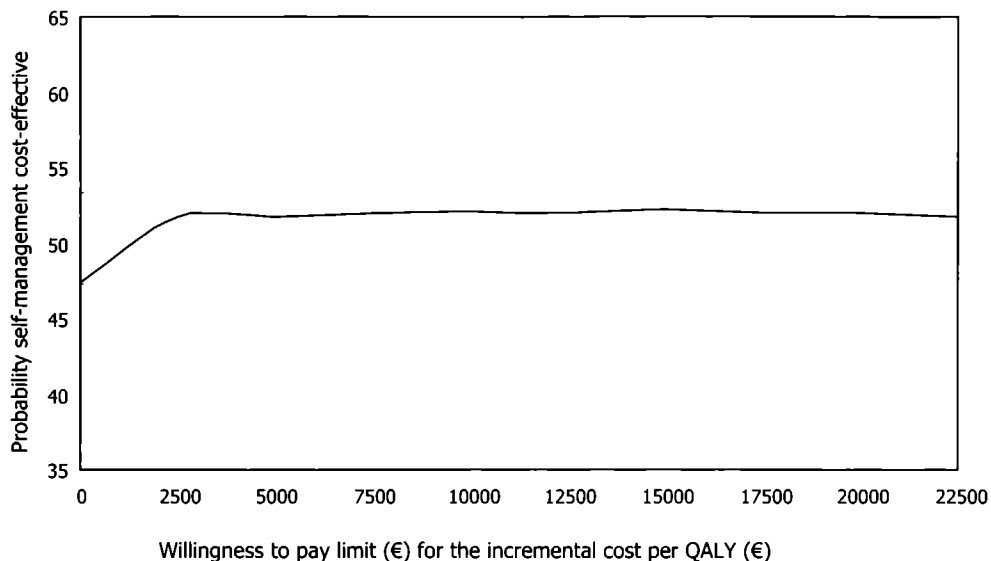
AQLQ: Asthma Quality of Life Questionnaire

MCID: minimal clinically important difference

QALY: quality-adjusted life year

95% CI: ninety-five percent confidence interval

Figure 7.6. Acceptability curve reflecting the probability that asthma self-management is cost-effective relative to usual care given a societal willingness-to-pay (λ) value



Discussion

This paper reports the economic evaluation of a family medicine based asthma self-management program, with 'usual care' according to Dutch asthma treatment guidelines as the comparator treatment. In summary, the results were as follows. Net savings in favour of self-management were observed in some of the direct health care cost components (i.e., use of budesonide and short-acting bronchodilators) and productivity ('indirect') cost. When all costs were included, a mean net saving of €13 in favour of self-management was observed (not statistically significant). Despite the investment necessary for program implementation, the total cost for the self-management group were significantly lower during the second year of follow-up. The Reference Case cost-effectiveness ratio pointed to self-management as a cost-effective treatment option: self-management dominated usual care (i.e., was more effective and less costly). However, the graphical evaluation of uncertainty around the cost per QALY estimate showed that the observed dominance of self-

management could not be firmly established. Overall, the secondary analyses based on successfully treated weeks and patients with a clinically important improved quality of life pointed to self-management as the dominant treatment option. When productivity cost were ignored, self-management was no longer dominant in the secondary analyses (€13,267 to gain one QALY and €33 to gain one successfully treated week).

Some comments on the studies' methodology need to be made before further discussing our findings. First, a disadvantage of using rating scales to value health states (and subsequently estimate QALYs) is that these instruments do not take risk avoidance and uncertainty about future health outcomes into account. Therefore, rating scale utilities tend to produce higher quality weights than other techniques such as time-trade-off and standard gamble methods⁴⁶. Moreover, rating scale scores appear to be not a true interval scale of preference for certain health states.

Unfortunately, in the current study we did not include a standard gamble or time-trade-off instrument. The mean number of QALYs in both treatment groups may have been overestimated because of this, but the incremental difference between the groups is probably valid. However, one should keep this point in mind when comparing our QALY results with external information from other studies.

We did not randomise individual asthma patients but family practices. The reason for doing so was to avoid potential 'contamination' of the usual care group by family physicians who had to practice both usual care and self-management simultaneously in different patients. Whereas in the clinical evaluation a multilevel analysis was used to address possible dependency in clustered observations induced by this kind of randomisation³⁴, some influence on the cost data cannot completely be ruled out. For instance, prevailing habits and preferences in prescribing bronchodilators by family physicians may have biased the results for this cost component to an unknown extent. The same argument holds for the promotion of influenza vaccination among asthmatics.

The baseline level of quality of life scores was higher in usual care patients, possibly leaving less room for improvement in this group. The comprehensive clinical evaluation of the data showed that the differences in AQLQ scores existing at baseline gradually disappeared during the 2-year follow-up period, which may

indicate that quality of life was maximised in both groups³³. However, the observation that self-management patients experienced significantly more successfully treated weeks implies that the self-management program also had an independent effect, regardless of the health status differences present at baseline. As a consequence of our study design, we cannot be sure which component of the self-management program in particular was responsible for the observed effects and savings: the (expensive) educational efforts made by the family physicians or the (relatively inexpensive) guidelines for self-monitoring and self-treatment. There is some evidence that addition of self-treatment guidelines to an asthma education program does yield extra effects in terms of health outcomes⁴⁴.

We have previously looked at the generalizability of our study population⁴⁸.

Evaluation of the recruitment process showed that patients who use a low or intermediate dosage of inhaled steroids were more likely to participate in the study than patients on a high dosage or patients who did not use inhaled steroids at all (although, according to our national treatment guidelines^{30,31}, they should have). Moreover, patients in paid employment were more likely to refrain from participation than those not in paid employment.

Regarding the cost analysis, several points need to be addressed. The most important expenditure necessary to implement the self-management program was the time spent by family physicians to educate and train their asthma patients (€113 per patient on average). Delegation of this task to, for instance, nurses specialised in respiratory care could reduce these cost considerably. Assuming delegation would not diminish program effectiveness, any reduction in the implementation cost would obviously affect cost-effectiveness ratios in favour of self-management. Another advantage of transferring the actual pursuance of self-management training to other professionals would be the diminished impact on the (already) high workload of family physicians. Targeting the self-management intervention to patients with a high likelihood of treatment success could also enhance overall efficiency, although at this time it is unknown how these patients could be identified beforehand.

One of the most remarkable findings in this study was that the introduction of self-management led to substitution of particular cost components with other components. For instance, the financial saving due to reduced budesonide usage and

less limited activity days in the self-management group was outweighed for the greater part by the extra out-of-pocket cost for domestic allergen avoidance measures, and, although to a much lesser extent, more influenza vaccinations and referrals to chest physicians. These favourable 'side effects' of the self-management program are probably explained by the emphasis put on the importance of healthy behaviour (i.e., allergen avoidance, influenza vaccination, smoking cessation) during the education sessions. The higher out-of-pocket cost for domestic allergen avoidance measures in the self-management group may be due to specific contents of our educational program. 'Nature, cause and prevention of allergy or allergic symptoms', 'Hyperreactivity and personal triggers', and 'Allergen avoidance measures at home' were three of the 31 educational topics the family physicians discussed with their participants. One previous study has reported that asthma education may be effective in promoting house dust mite avoidance measures in patients with moderate to severe asthma⁴⁹. The extra attention focussed on self-management patients as a consequence of the intensified doctor-patient relationship may have influenced the higher referral rate observed in the self-management group. We observed significant differences in the use of asthma medication between self-management and usual care patients, especially for budesonide. This difference suggests a more efficient use of prophylactic medication due to self-management, a finding inconsistent with previously reported higher compliance rates regarding the use of inhaled steroids after introducing self-management^{4,50}. However, use of the term 'compliance' may be inappropriate when it comes to evaluation of self-management in patients with asthma. After all, the essence of the approach is to fine-tune the use of inhaled steroids to the actual need as determined by self-monitoring, without a prescribed (fixed) daily dose. For this reason, we anticipated a reduced consumption of inhaled steroids in the intervention group beforehand, although it has been shown that self-management patients do not always adhere to their personalised self-treatment guidelines⁴.

The main objective of any self-management program is to attain a longwearing behavioural change in patients with regard to their disease. Once accomplished, this effect could be expected to persist for a longer period of time. Although in the current study we had to limit the time horizon to a maximum of two years, there was

a tendency towards further productivity cost reduction during the second year of follow-up. Because we had no cost data from the years before the study at our disposal, we can only speculate on how the observed productivity cost for the first and second year related to the annual productivity cost before the study. However, both Mühlhauser *et al*²⁰ and Trautner *et al*²⁵ have shown that significant changes from the pre-study situation may indeed be achieved. Moreover, findings reported by Trautner *et al*²⁵ agree with our observation of a progressive reduction of productivity cost between the first and second year in self-management patients: they observed a 5% reduction in the number of days of absence from work during the first year, but an 18% reduction during the third year. This suggests that savings in productivity cost resulting from asthma self-management are retained in the long term.

Several other authors have reported significantly lower productivity cost due to self-management as well^{17-19;22;23;26;27}. The estimated savings from these studies range from 25 to 70% of the productivity cost observed in control patients. It should, however, be kept in mind that these studies were performed in populations with varying asthma severity, with diverse control groups, in different countries and with different methods used for valuing productivity losses. Since there is no consensus in the literature as to what method is most suitable for valuing productivity losses, we applied the widely used human capital approach. An alternative method would have been the more advanced friction cost method as proposed by Koopmanschap *et al*⁷. The basic idea of this method is that the amount of production lost due to disease depends on the time-span organisations need to restore the initial production level. This 'friction period' is likely to differ by location, industry, firm and category of worker, making the method rather complex. Had we used the friction cost method, our estimate of productivity cost would probably have been lower, as has been demonstrated for other health care programs⁴⁸.

It is generally recognised that a large proportion of the total cost of asthma is derived from treating the consequences of poor asthma control, such as emergency room use and hospitalizations⁵. Therefore, improved asthma control is likely to reduce the number of acute asthma-related hospital admissions as well as the productivity costs resulting from the admission itself and recovery time after

discharge. Although several authors have reported reductions in use of hospital services due to self-management, hospital admissions did not occur at all in our study and can therefore be no explanation for the lower number of sick days observed in self-management patients. Thus, the effect of self-management on asthma-related limited activity days appears to be more subtle in mild patients with adequate asthma control, like the patients involved in the current study. We conclude that guided self-management is a safe and cost-effective alternative approach compared to asthma treatment usually provided in Dutch primary health care.

References

1. Hedman J, Kaprio J, Poussa T, Nieminen MM. Prevalence of asthma, aspirin intolerance, nasal polyposis and chronic obstructive pulmonary disease in a population-based study. *Int J Epidemiol* 1999;28:717-722.
2. Hahn DL, Beasley JW. Diagnosed and possible undiagnosed asthma: a Wisconsin Research Network (WReN) Study. *J Fam Pract* 1994;38:373-379.
3. Tettersell MJ. Asthma patients' knowledge in relation to compliance with drug therapy. *J Adv Nurs* 1993;18:103-113.
4. Van der Palen J, Klein JJ, Rovers MM. Compliance with inhaled medication and self-treatment guidelines following a self-management programme in adult asthmatics. *Eur Respir J* 1997;10:652-657.
5. Barnes PJ, Jonsson B, Klim JB. The costs of asthma. *Eur Respir J* 1996;9:636-642.
6. Lahdensuo A. Guided self management of asthma--how to do it. *BMJ* 1999;319:759-760.
7. Neville R. Patient education and guided self-management plans. *Resp Med* 1996;90:385-386.
8. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ, Walters EH. Self-management education and regular practitioner review for adults with asthma (Cochrane Review). *The Cochrane Library Issue 3*. 2000. Oxford: Update Software.
9. Liljas B, Lahdensuo A. Is asthma self-management cost-effective? *Patient Educ Couns* 1997;32:S97-S104.
10. British Thoracic Society. The British Guidelines on Asthma Management 1995 Review and Position Statement. *Thorax* 1997;52:S1-S21.
11. Anonymous. Global strategy for asthma management and prevention NHLBI/WHO workshop report. 95-3659; National Heart, Lung and Blood Institute: 1995.
12. Thoonen BPA, Jones KP, van Rooij HA, van den Hout AC, Smelee I, Grol R, van Schayck. CP. Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view. *Fam Pract* 1999;16:117-122.
13. Barner JC, Mason HL, Murray MD. Assessment of asthma patients' willingness to pay for and give time to an asthma self-management program. *Clin Ther* 1999;21:878-894.

14. Partridge MR, Hill SR. Enhancing care for people with asthma: the role of communication, education, training and self-management. 1998 World Asthma Meeting Education and Delivery of Care Working Group. *Eur Respir J* 2000;16:333-348.
15. Drummond N, Abdalla M, Buckingham JK, Beattie JAG, Lindsay T, Osman LM, Ross SJ, Roy-Chaudhury A, Russell I, Turner M. Integrated care for asthma: a clinical, social, and economic evaluation. Grampian Asthma Study of Integrated Care (GRASSIC). *BMJ* 1994;308:559-564.
16. Wilson SR, Scamangas P, German DF, Hughes GW, Lulla S, Coss S, Chardon L, Thomas RG, Starr-Schneidkraut N, Stancavage FB, Arsham GM.. A controlled trial of two forms of self-management education for adults with asthma. *Am J Med* 1993;94:564-575.
17. Taitel MS, Kotses H, Bernstein IL, Bernstein DI, Creer TL. A self-management program for adult asthma. Part II: Cost- benefit analysis. *J Allergy Clin Immunol* 1995;95:672-676.
18. Bolton MB, Tilley BC, Kuder J, Reeves T, Schultz LR. The cost and effectiveness of an education program for adults who have asthma. *J Gen Intern Med* 1991;6:401-407.
19. Sondergaard B, Davidsen F, Kirkeby B, Rasmussen M, Hey H. The economics of an intensive education programme for asthmatic patients. A prospective controlled trial. *Pharmacoeconomics* 1992;1:207-212.
20. Muhlhauser I, Richter B, Kraut D, Weske G, Worth H, Berger M. Evaluation of a structured treatment and teaching programme on asthma. *J Intern Med* 1991;230:157-164.
21. Windsor RA, Bailey WC, Richards JM, Manzella B, Soong SJ, Brooks M. Evaluation of the efficacy and cost effectiveness of health education methods to increase medication adherence among adults with asthma. *Am J Public Health* 1990;80:1519-1521.
22. Lahdensuo A, Haahtela T, Herrala J, Kava T, Kiviranta K, Kuusisto P, Pekurinen M, Peramäki E, Saarelainen S, Svahn T, Liljas B. Randomised comparison of cost effectiveness of guided self management and traditional treatment of asthma in Finland. *BMJ* 1998;316:1138-1139.
23. Kauppinen R, Sintonen H, Vilkkä V, Tukiainen H. Long-term (3-year) economic evaluation of intensive patient education for self-management during the first year in new asthmatics. *Resp Med* 1999;93:283-289.
24. Neri M, Migliori GB, Spanevello A, Berra D, Nicolini E, Landoni CV, Ballardini L, Sommaruga M, Zanon P. Economic analysis of two structured treatment and teaching programs on asthma. *Allergy* 1996;51:313-319.

25. Trautner C, Richter B, Berger M. Cost-effectiveness of a structured treatment and teaching programme on asthma. *Eur Respir J* 1993;6:1485-1491.
26. Ghosh CS, Ravindran P, Joshi M, Stearns SC. Reductions in hospital use from self management training for chronic asthmatics. *Soc Sci Med* 1998;46:1087-1093.
27. Gallefoss F, Bakke PS. Cost-effectiveness of self-management in asthmatics: a 1-yr follow-up randomized, controlled trial. *Eur Respir J* 2001;17:206-213.
28. Gold MR, Siegel JE, Russell LB, Weinstein MC. Cost-effectiveness in health and medicine. New York: Oxford University Press; 1996.
29. Drummond MF, O'Brien B, Stoddart GL, Torrance GW. Methods for the economic evaluation of health care programmes. Oxford: Oxford University Press; 1997.
30. van der Waart MAC, Dekker FW, Nijhoff S, Thiadens HA, van Weel C, van Schayck CP, Helder M, Rosmalen CFH. [NHG guideline on CNSLD in adults: treatment]. *Huisarts Wet* 1992;35:437-443.
31. Geijer RMM, van Hensbergen W, Bottema BJAM, van Schayck CP, Sachs APE, Smeele IJM, Thiadens HA, van Weel C, van der Zwan AAC, Rosmalen CFH. [NHG guideline on asthma in adults: treatment]. *Huisarts Wet* 1997;40:443-454.
32. Wever-Hess J, Wever AMJ. Asthma statistics in the Netherlands 1980-94. *Respir Med* 1997;91:417-422.
33. Thoonen BPA, Schermer TRJ, van Schayck CP. Self-managed asthma education diminishes the risk of underestimating information needs of asthma patients. *Prim Care Respir J* 2000;9:39.
34. Thoonen BPA, Schermer TRJ, van Weel C, Grol R, van Schayck CP. Clinical effectiveness of self management of asthma in general practice: a randomised controlled trial. *Eur Resp J* 2001;18(Suppl 33):518S.
35. Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health related quality of life in asthma: development of a questionnaire for use in clinical trials. *Thorax* 1992;47:76-83.
36. Rand CS, Wise RA. Measuring adherence to asthma medication regimens. *Am J Respir Crit Care Med* 1994;149:S69-76.
37. Anonymous. Pharmacotherapeutic compass 2000/2001. Amstelveen; Dutch College of Health Insurance: 2000.

38. Anonymous. Diagnostic compass 1999/2000. Amstelveen; Dutch College of Health Insurance: 1999.
39. Oostenbrink JB, Koopmanschap MA, Rutten, FFH. Guidebook for cost investigation. Amstelveen; Dutch College of Health Insurance: 2000.
40. Rutten-van Molken MP, Custers F, van Doorslaer EK, Jansen CC, Heurman L, Maesen FP, Smeets JJ, Bommer AM, Raaijmakers JA. Comparison of performance of four instruments in evaluating the effects of salmeterol on asthma quality of life. *Eur Respir J* 1995;8:888-898.
41. Bijl-Hofland ID, Folgering HTM, Van den Hoogen H, Cloosterman SGM, Van Weel C, Donkers JM, Van Schayck CP. Perception of bronchoconstriction in asthma patients measured during histamine challenge test *Eur Respir J* 1999;14:1049-1054.
42. Thompson SG, Barber JA. How should cost data in pragmatic randomised trials be analysed? *BMJ* 2000;320:1197-1200.
43. Severens JL, De Boo TM, Konst EM. Uncertainty of incremental cost-effectiveness ratios. A comparison of Fieller and bootstrap confidence intervals. *Int J Technology Assessment Health Care* 1999;15:608-614.
44. Willan AR, O'Brien BJ, Leyva RA. Cost-effectiveness analysis when the WTA is greater than the WTP. *Stat Med* 2001;20:3251-3259.
45. Fenwick E, Claxton K, Sculpher M. Representing uncertainty: the role of cost-effectiveness acceptability curves. *Health Econ* 2001;10:779-787.
46. Nord E. The validity of a visual analogue scale in determining social utility weights for health states. *Int J Health Plann Manage* 1991;6:234-242.
47. Klein JJ, van der Palen J, Uil SS, Zielhuis GA, Seydel ER, van Herwaarden CLA. Benefit from the inclusion of self-treatment guidelines to a self-management programme for adults with asthma. *Eur Respir J* 2001;17:386-394.
48. Thoonen BPA, Schermer TRJ, Akkermans RP, den Otter JJ, Grol RP, van Schayck CP. Willingness of patients to perform self-management of asthma and the role of inhaled steroids. *Scan J Prim Health Care*. 2002;20:60-4.
49. Cote J, Cartier A, Robichaud P, Boutin H, Malo JL, Rouleau M, Boulet LP. Influence of asthma education on asthma severity, quality of life and environmental control. *Can Respir J* 2000;7:395-400

50. Gallefoss F, Bakke PS. How does patient education and self-management among asthmatics and patients with chronic obstructive pulmonary disease affect medication. *Am J Respir Crit Care Med* 1999;160:2000-2005.

51. Koopmanschap MA, Rutten FFH, van Ineveld BM, van Roijen L. The friction cost method for measuring indirect costs of disease. *J Health Economics* 1995;14:171-189.

52. Koopmanschap MA, Rutten FF. The impact of indirect costs on outcomes of health care programs. *Health Econ* 1994;3:385-393.

Chapter 8

Self management in asthma care

Professionals must rethink their role if they are to guide patients successfully

Bart Thoonen, General practitioner

Chris van Weel, professor of general practice

Published in: BMJ 2000;321:1482-83

And BMJ-USA 2001;1:12-3

'Equipping people with asthma with the tools they need to manage their condition is as important as writing the correct prescription,' according to the United Kingdom's National Asthma campaign. Guided self management has an established place in asthma guidelines and recommendations^{1;2}. Yet the reality of every day asthma care is quite different from that which the guidelines suggest, as shown by Jones et al in this issue (p 1507).³ Even among general practitioners in an academic setting, asthma remains underdiagnosed and poorly treated,⁴ despite increased awareness of the condition. Professionals perceive asthma as a lifelong problem, but patients discontinue treatment after a few years or do not consult health professionals at all.⁵ General practitioners and nurses have an important role in implementing self care programmes. However, Jones et al report that patient self management and transfer of responsibility from professional caregivers received a lukewarm response at best from general practitioners, practice nurses, and patients. This is particularly striking among nurses, who are generally valued for their ability to implement protocols, including encouraging self care. This response could be related to specific characteristics of the programme, but more probably it signals a development in primary care nursing in which nurses are no longer prepared only to follow instructions but wish to act using their professional judgement. There are indications that nurses need specific asthma qualifications to provide the best possible care for patients with asthma. Robertson et al found that nurses with advanced qualifications in asthma provided self management plans significantly more frequently.⁶ Ownership of guidelines is essential to guaranteeing implementation, not only for general practitioners but also nurses.

The nurses in the study by Jones et al believed strongly that guided self management plans might do more harm than good as these plans would 'increase the likelihood of patients falling into bad habits'. The nurses believed that self management plans were appropriate for just a few patients: the ones who were already almost fully compliant with their treatment regimens. The nurses' lack of faith in the effectiveness of self management plans and their reluctance to hand over responsibilities to the patient contradict the very basis of self management. The objective of self management is to empower patients with the knowledge and skills they need to treat their own illness. A first step towards this is to have patients share

responsibility for their treatment with their caregivers.⁷ But empirical data on asthma care can only serve to indicate the breadth of the differences. For example, a general practice based screening programme in the Netherlands found that about 75 % of those with mild asthma and 65 % of those with moderately severe asthma who were eligible for treatment were reluctant to visit their general practitioner or to comply with follow up^{7;8}; most of the patients studied did not consider themselves ill.⁹ In the study by Jones et al patients stated that they were not interested in guided self management plans, describing themselves as 'already self managing competently' and 'behaving responsibly'. This reflects self reliance more than competent self management according to guidelines.

It also indicates a failure to integrate the personal and the medical dimensions of medical care¹⁰ – that is, the integration of the medical agenda with the patient's perspective. Self management schemes have to combine the best of these two elements, but sharing responsibilities implies that patients as well as medical professionals should determine the goals of treatment. Ownership of a management plan is an important precondition to effective treatment for both patients and health professionals. It is not a question of whether guided self management is effective or should be implemented, but rather the challenge is to accept that patients are managing their care one way or another and that we need to create opportunities to clarify how medical input can enhance their personal situation. Cooperation is the key to bridging the gap between the efficacy and effectiveness of asthma care.

References

1. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ *et al.* Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev* 2000;3:CD001117.
2. Meijer RJ, Kerstjens HAM, Postma DS. Comparison of guidelines and self management plans in asthma. *Eur Resp J* 1997;10:1163-72.
3. Jones A, Pill R, Adams S. Qualitative study of views of health professionals and patients on guided self management plans for asthma. *BMJ* 2000;321:1507-10.
4. Tirimanna PR, van Schayck CP, den Otter JJ, van Weel C, van Herwaarden CL, Van den Boom G *et al.* Prevalence of asthma and COPD in general practice in 1992: has it changed since 1977? *Br J Gen Pract* 1996;46:277-81.
5. Kolnaar B, Beissel E, van den Bosch WJ, Folgering H, van den Hoogen HJ, van Weel C. Asthma in adolescents and young adults: screening outcome versus diagnosis in general practice. *Fam Pract* 1994;11:133-40.
6. Robertson R, Osman LM, Douglas JG. Adult asthma review in general practice: nurses' perception of their role. *Fam Pract* 1997;14:227-32.
7. Thoonen BPA, Schayck CPv, Weel Cv, Levy M, Spelman R, Price D *et al.* Present and future management of asthma and COPD: proceedings from WONCA 1998. *Fam Pract* 1999;16:312-5.
8. van Grunsven PM, van Schayck CP, van Kollenburg HJ, van Bosheide K, van den Hoogen HJ, Molema J *et al.* The role of "fear of corticosteroids" in nonparticipation in early intervention with inhaled corticosteroids in asthma and COPD in general practice. *Eur Respir J* 1998;11:1178-81
9. van den Boom G, van Schayck CP, van Mollen MP, Tirimanna PR, den Otter JJ, van Grunsven PM *et al.* Active detection of chronic obstructive pulmonary disease and asthma in the general population. Results and economic consequences of the DIMCA program. *Am J Respir Crit Care Med* 1998;158:1730-8.
10. Sweeney KG, MacAuley D, Gray DP. Personal significance: the third dimension. *Lancet* 1998;351:134-6.

Chapter 9

Role of family physicians in implementing asthma self-management programs

BPA (Bart) Thoonen, MD

Prof C (Chris) van Weel, MD, PhD

Dept of General Practice / Family practice, University Medical Centre Nijmegen, The Netherlands

Published in: Disease Management and Health Outcomes 2002;10:141-6

Abstract

The reality of every day asthma care differs substantially from guidelines. The fact that better possibilities for asthma care do not result in a better outcomes remains an enigma and harms professional pride. Patient self-management has been presented as a tool to improve outcome of care. Based on published work thus far, it can be concluded that self-management of asthma can be beneficial from both the family physicians' and the patients' perspective and, under certain conditions, proves to be an efficient method of incorporating both interests. Health professionals play an important role in implementing self-care, but several barriers should be solved first: attitudes of health professionals and patients need to shift towards shared responsibilities and be patient-centered and organization of care should change accordingly. As reviewed in this article, the typical features of self-management of asthma may provide the means to overcome these barriers.

Introduction

Guided self-management has an established position in asthma guidelines and recommendations^{1,2}. Yet, the reality of every day asthma care differs substantially from these guidelines, and under-diagnosis and under-treatment remain high, even under optimal academic primary care³, and despite the fact that family physicians are increasingly aware of this problem⁴.

Patient-related factors are important in under-diagnosis and under-treatment: patients appear reluctant to consult for chronic, persistent respiratory symptoms⁵ or discontinue treatment that was prescribed for long-term use after a short while. In particular, there is resistance to pharmacological treatment⁶: this has been reported in as many as 75 % of patients with mild asthma and in 65 % of those with moderately severe asthma. Additionally, most patients consider themselves as not being ill^{3,6}.

This information in itself is not new for family physicians and nurses, but it conflicts fundamentally with professional concepts of 'good' asthma care, which focuses on a pro active approach and the effective prevention of symptomatic episodes of asthma. This makes it difficult to apply the knowledge of patients' perceptions in a constructive way in regular care.

The fact that better possibilities (e.g. inhaled corticosteroids, patient education materials, leukotriene antagonists) do not always result in better outcomes remains an enigma and harms professional pride. Patient self-management has been presented as a tool to improve the outcome of care, assuming that improved knowledge, self-efficacy and patients' attitudes would enhance compliance with professional treatment schemes⁷. But the discrepancy between what is possible from a professional perspective and what is desired from the patients' perspective makes this an over-simplification. Based on this model, 'self-management' as mere compliance enhancement could easily become yet another way of pursuing professional objectives by other means. In other words, it is the physician who wants the patient to become compliant to the physicians' treatment scheme, instead of the patient becoming motivated to take and maintain control by himself.

The findings of Jones et al⁸ that patients, family physicians and nurses are less than enthusiast to use and promote self-management plans under these conditions may not come as a surprise. Nurses in particular are generally valued for their ability to implement protocols and promote patient involvement, so this is in our view an important signal from primary care. At the same time, it is sound professional judgement that the basic concept of current asthma care, including the contribution of self-management, must be reconsidered before effective treatment will be feasible.

The implementation of self-management can benefit from experiences associated with the implementation of other care innovations – for example, the introduction of treatment guidelines. These experiences have underlined that ownership of a treatment plan is essential, and this must also be true for self-management guidelines. All involved should experience this feeling of ownership; the interesting concept of 'self-management' makes it explicit that this includes, in particular, the ability of patients to take ownership of the guideline or plan. Their needs, demands and expectations must be taken into account, this will allow for a better understanding of why they cannot subscribe to the professional norms of asthma care. Understanding and cooperation are the first steps in eventually closing the gap between what is possible and what can be achieved in practice.

No guideline can reconcile what is incompatible. However, when it is explicitly clear where a patient and provider might differ, then at least informed decisions can be made and differences of opinion understood. This also allows for a re-evaluation of treatment decisions in a late phase. Based on this viewpoint, the key feature of self-management is the change to patients fully sharing responsibility of treatment with their caregivers⁹, based on a common frame of reference. It is in this context that health professionals play an important role in implementing self-care, although some barriers may be encountered. Interviews with British GPs suggest that these obstacles are mainly of a practical nature¹⁰ Necessary materials (e.g. peak flow devices, diary cards) need to be available and an extra investment of time is required when initiating a self-management program, including the setting up of an asthma clinic and dividing tasks between all the health professionals involved. Absence of a clear protocol of care to support this proved to be one of the most important obstacles in implementation of these programs. Practitioners should therefore look for evidence of the effectiveness of self-management under circumstances where these issues are addressed and the barriers taken care of. We will review and summarize the benefits and essential elements of self-management on which such protocol of care can be based.

Benefits of self-management

The first publications regarding self-management of asthma date from the late 1970s and studies, including those of self-medication, started in the 1980s¹¹⁻¹⁷. Table 9.1 summarises the most important results of various trials published since this date. These studies have indicated that self-management programs are capable of reducing hospital admissions and emergency room visits in outpatient clinics and emergency departments. Days off work can be reduced and quality of life has been improved. One recent study demonstrated that having an asthma action plan was associated with a 70% reduction in the risk of asthma-death¹⁸.

Thus far, there are few randomised controlled trials evaluating the effects of guided self-management programs in family practice, which raises the question of whether guided self-management may also be effective in patients with mild asthma. Loss of asthma control occurs less frequently in this group and there is less impact on quality

of life¹⁹. Consequently, the room for improvement of a self-management program is limited. Hoskins et al demonstrated reductions in morbidity in terms of hospital admission, emergency consultations, oral steroid courses and emergency nebulizations; however, because of possible selection bias, the superiority of self-management plans could not be proven²⁰ Their results suggest that improvements in clinical and morbidity parameters are indeed less likely to occur in patients with mild asthma. Jones et al. Also reached this conclusion, although their failure to demonstrate superiority of self management may be due to a lack of statistical power to detect minor changes in a population with relatively little room for improvement²¹. Based on published work thus far it may be concluded that, under certain conditions, self-management of asthma is beneficial from both the family physicians' and the patients' perspective and proves to be an efficient method of incorporating both interests.

Table 9.1: Effects of asthma self management programs

1st author / pub year	Setting / patients	Self-management program	Outcomes
Snyder et al. (16)	97 asthmatics with at least mild asthma, selected through advertisements; no previous self management	Two 2.5-hour group asthma education sessions. Compared with a waiting list group	3-months follow-up: increased asthma knowledge, reduction in frequency of asthma attacks
Beasley et al. (17)	36 asthma clinic outpatients (aged 14-60y); initial mean FEV ₁ 75.6 % of predicted value.	Three sessions over 3 months, including skills training. Peak flow based, with a stepwise doubling of inhaled steroids / oral prednisolone. No control group.	6-months follow-up: increased FEV ₁ , FVC (both % predicted value), reduction in nocturnal waking and lost productivity. Reduction in oral and inhaled corticosteroids and antibacterials used
Bailey et al. (30)	225 asthma patients (aged >18y) with mild to severe asthma attending a university pulmonary	One-on-one 1-hour counselling session with telephone follow-up at 2 and 4 weeks. Patient workbook aimed at increasing	1-year follow-up: increased inhaler skills and adherence to inhaler treatment. Decrease in

1st author/ pub year	Setting / patients	Self-management program	Outcomes
	medicine clinic.	cognitive skills, positive attitude and enhanced compliance. Compared with usual care	asthma symptoms/bother in previous 7 days. Decrease in episodes of cough/shortness of breath and asthma interference in daily life. Decreased emergency departmentt visits.
D'Souza et al. (31)	69 Maori patients (aged 14-65 y) with moderate to severe asthma	Instructed by doctors in the study team at a community clinic. Peak flow and symptom based, stepwise doubling of inhaled steroids / oral prednisolone. 8-weeks before compared with 16 weeks of self-management. No control group	After 16 weeks' self-management: 12 % increase in mean peak flow. Reduction in night awakenings, days out of action and unscheduled / emergency visits. Increase in the number of patients prescribed inhaled corticosteroids and a decrease in those solely using oral bronchodilators.
Allen et al. (32)	116 patients (aged 18-65y) with moderate to severe asthma responding to newspaper advertisements	Hospital-based program with 4 once-weekly small group 2.5 hour education sessions focussing on asthma management skills and behaviour. Compared with control group.	1-year follow-up: improved asthma knowledge. Reduction in morning wheeze and bronchodilator requirement
Ignacio-Garcia et al. (33)	70 asthma clinic outpatients (aged 14-65y), recruited at attendance	One individual 30-min education session. Peak flow based, with stepwise doubling of inhaled steroids / oral prednisolone. Compared with control group receiving placebo education	6-months follow-up: improvements in the number of exacerbations, physician consultations / emergency room visits, days lost from work, days on antibacterials and mean peak flow values. Decreased peak flow

1st author/ pub year	Setting / patients	Self-management program	Outcomes
			variability, and use of inhaled fenoterol and prednisone
Kotses et al. (34)	76 patients (aged 27-70y) with asthma.	Seven 90-minute once-weekly small group sessions, including skills training and education. Asthma management behaviour regulated through environmental cues. Compared with a waiting list control group for the first 6 months, and the period prior to self-management (before/after design) for the 16-20 month follow up	Short-term (6 months): reduction in asthma symptoms and physician visits Improved asthma management skills and cognitive abilities Long term (16-20 months): reduction in frequency of asthma attacks and use of medication. Improved cognitive measures and management skills.
Taitel et al. (35)	76 patients (aged 27-70y) with asthma Cost-benefit analysis	Seven 90-minute once-weekly small group sessions, including skills training and education. Asthma management behaviour regulated through environmental cues. Compared with a waiting list control group for the first 6 months, and the period prior to self-management (before/after design) for the 16-20 month follow up	Cost-benefit ratio of 1:2.28
Jones et al (21)	127 patients (aged 15-40y) predominantly with mild asthma, from 25 family practices	Two education sessions over 2 weeks. Peak flow based, with stepwise doubling of inhaled steroids / oral prednisolone. Compared with usual care.	26-weeks follow-up. no-between group differences in lung function, symptoms, quality of life and prescribing costs.
Ayres / 1996 (36)	125 outpatients with persistent mild to moderate asthma (aged >17y)	Peak flow based, stepwise doubling of inhaled steroids / oral prednisolone. Compared with physician-managed	Reductions in sleep disturbance, daytime symptoms and activity scores in both groups; no

1st author/ pub year	Setting / patients	Self-management program	Outcomes
		regime based on the same criteria.	significant difference between groups.
Hoskins et al. (20)	906 asthma patients attending 159 family physicians	Peak flow based, stepwise doubling of inhaled steroids / oral prednisolone. Compared with usual care.	6-months follow-up: reduction in hospital admissions, asthma symptom consultations, asthma review consultations, courses of oral steroids and use of emergency nebulized bronchodilators
Lahdensuo et al. (37)	115 outpatients with mild to moderate asthma	Peak flow based, stepwise doubling of inhaled steroids / oral prednisolone. Compared with usual care	1-year follow-up: cost-effectiveness analysis demonstrated an increase in the number of healthy days and lower total costs
Kauppinen et al. (38)	162 outpatients (aged 18-76y) with newly diagnosed asthma	Intensive patient education, skills training and supervision Peak flow based, stepwise doubling of inhaled steroids / oral prednisolone in both treatment groups. Compared with conventional education at the baseline visit only	3-year follow-up. Improvements in FEV ₁ and peak flow values. Lower risk ratio for the number of days with sickness. Lower average cost of primary care services and antibacterials
Klein et al. (39)	245 outpatients with moderate to severe asthma	Self-management education in both groups with addition of peak-flow based treatment guidelines in the experimental group	After 1 year better perceived asthma control and self confidence. 2-year follow-up: improvement in quality of life, peak-flow variability and number of outpatient visits No between-group differences

Self-management programs: essential contents

Self-management programs revolve around shared responsibilities. The patient is responsible for dealing with asthma in everyday life. On the other hand, the health professional provides patients with the necessary knowledge, skills and attitudes needed for decision making, and coaches the patient into modifying their behaviour and autonomy.

It is currently believed that interventional programs, using a combination of education, skills training and methods to modify behaviour, are needed to optimise management and improve the quality of life in patients with asthma^{22;23}. Patient education alone does not reduce hospitalisations, doctor visits or medication use in asthma but may play a role in improving patients' perceptions of their symptoms²⁴. Within this context, it is obvious that patient education should be tailored to the patients' individual needs and be preceded by a proper assessment of what these needs are. Systematically making an inventory of the patients' needs or concerns prior to each office visit has shown to improve patient-physician interaction²⁵.

Solely taking the patients' perspective into account can be too limited, as there may be a discrepancy between what the patient wants to know, on the basis of own interests or previous knowledge, and what the patient needs to know according to the health professional. It is the family physician's responsibility to increase patient awareness of the existence and importance of certain information and possibilities. This may depend on the relevance to the patient of the presented topic and whether they feel it deserves further attention or not, resulting in further integration of the patient's agenda and the medical perspective.

The cornerstone of self-management is self-monitoring. It gives patients the opportunity to give feedback on decisions they make regarding their asthma and medications. There are two major sources of feedback: self-assessed symptoms and peak flow values. It is currently believed that waking at night due to asthma and increased use of bronchodilator provide the most sensitive measurements of clinical deterioration²⁶. Another useful indicator of asthma control is the patient's peak flow. When related to the patient's best value, this parameter can provide information on both deterioration and control of asthma; the latter factor being the incentive for reducing or temporarily stopping inhaled steroids. There is ongoing debate as to

whether self-management should be symptom based, peak-flow based or a combination of both. A systematic review performed by the Australian National Asthma Campaign indicated that there was no difference between these two forms of self-monitoring, but available data on this topic were limited²⁷⁻²⁹.

Role of the family physician

Key elements of self-management are patient education and skills training, providing the patient with specific instructions on avoidance measures and when and how to take preventive and reliever medication. Most of these elements are already advocated in asthma care guidelines and should be part of routine clinical practice. The difference with asthma care described in guidelines and self-management, however, is the change in attitude of both health professionals and patients. Health professionals may need to learn to accept that patients will not always take the clinically most desired decision. However, as providers of healthcare, they remain responsible for optimising the circumstances under which patients can make these decisions; in other words, they need to enhance knowledge and self-efficacy. Patients, on the other hand, need to shift from relying on their physician as the person telling them what to do, towards feeling more responsible for their own choices and showing a willingness to explore their own possibilities. This does not mean that patients should be left on their own. Instead, self-management must be seen as a contemporary strategy for enhancing patient autonomy.

Key elements of self-management are the use of tools to provide the patient with the necessary background to make daily decisions on how to deal with asthma. Self-management thus becomes a process of ongoing 'problem-based learning' instead of mere compliance enhancement. Continuity of care and the possibility of regular review of patients are typical qualities of the primary-care setting, which may provide a perfect basis to continuously pursue better self-management in a patient-centered framework. On the other hand, the investment of time required to stepwise educate and train patients initially appears to be a prohibitive factor. But it is here that the chronicity of asthma works as an advantage. Asthma is considered to be a life-long disease and is usually clinically manifest for at least several years. This should be

kept in mind, when assessing the time investment. Education, training and coaching can take place over a number of consultations and need not be provided solely by the physician. Most of these required tasks may easily be delegated to practice nurses. It is the role of the family physician to ensure continuity of care in terms of offering the patient a consistent program in which all partners (physician, nurse, patient) share the same attitudes and principles. Setting up an asthma clinic where all of these partners are involved may provide the framework for such consistency.

Conclusion

Becoming more or less fully self-managing is an ongoing process that will inevitably take some time, but the long-term it is time saving. It is the responsibility of the health professional to elucidate this long-term perspective to patients and thus initiate growth of a patient-partnership towards a common agenda. To achieve patient's self-monitoring of signs and symptoms is also a crucial part. It allows self-validation of the importance and meaning of these signs and symptoms in terms of their impact on daily life and their relationship to autonomous decision making. This will form the basis of actual self-intervention. Coaching directed at the 'therapeutic' implications of monitored signs and symptoms can highlight the agreement and discrepancies between the views of patients and professionals.

Rearranging the organisation and delivery of asthma care into a mode of cooperation that aims at shared responsibilities and is patient-centered may very well be the key to bridge or narrow the gap between efficacy and effectiveness of asthma care. The typical features of self-management of asthma provide a means for such mode of cooperation.

References

1. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ et al. Self-management education and regular practitioner review for adults with asthma (Cochrane Review). The Cochrane Library Issue 3. 2000. Oxford: Update Software.
2. Meijer RJ, Kerstjens HA, Postma DS. Comparison of guidelines and self management plans in asthma. *Eur Resp J* 1997; 10(5):1163-1172.
3. van den Boom G, van Schayck CP, van Mollen MP, Tirimanna PR, den Otter JJ, van Grunsven PM et al. Active detection of chronic obstructive pulmonary disease and asthma in the general population. Results and economic consequences of the DIMCA program. *Am J Respir Crit Care Med* 1998; 158(6):1730-1738.
4. Tirimanna PR, van Schayck CP, den Otter JJ, van Weel C, van Herwaarden CL, Van den Boom G et al. Prevalence of asthma and COPD in general practice in 1992: has it changed since 1977? *Br J Gen Pract* 1996; 46(406):277-281.
5. Kolnaar B, Beissel E, van den Bosch WJ, Folgering H, van den Hoogen HJ, van Weel C. Asthma in adolescents and young adults: screening outcome versus diagnosis in general practice. *Fam Pract* 1994; 11(2):133-140.
6. van Grunsven PM, van Schayck CP, van Kollenburg HJ, van Bosheide K, van den Hoogen HJ, Molema J et al. The role of "fear of corticosteroids" in nonparticipation in early intervention with inhaled corticosteroids in asthma and COPD in general practice. *Eur Respir J* 1998; 11(5):1178-1181.
7. Bandura AB. Social learning theory. Englewood Cliffs, N.J.: Prentice-Hall, 1977.
8. Jones A, Pill R, Adams S. Qualitative study of views of health professionals and patients on guided self management plans for asthma. *BMJ* 2000; 321(7275):1507-1510.
9. Thoonen BPA, Schayck CPv, Weel Cv, Levy M, Spelman R, Price D et al. Present and future management of asthma and COPD: proceedings from WONCA 1998. *Fam Pract* 1999; 16(3):312-315.
10. Thoonen BPA, Jones KP, Rooij HAv, Hout ACvd, Smeele I, Grol R et al. Self-treatment of asthma: possibilities and perspectives from the practitioner's point of view. *Fam Pract* 1999; 16(2):117-122.
11. Maiman LA, Green LW, Gibson G, MacKenzie EJ. Education for self-treatment by adult asthmatics. *JAMA* 1979; 241:1919-1922.
12. Fireman P, Friday GA, Gira C, Vierthaler WA, Michaels L. Teaching self-management skills to asthmatic children and their parents in an ambulatory care setting. *Pediatrics* 1981; 68(3):341-348.

13. Hindi-Alexander MC, Cropp GJ. Evaluation of a family asthma program. *J Allergy Clin Immunol* 1984; 74(4 Pt 1):505-510.
14. Whitman N, West D, Brough FK, Welch M. A study of a Self-Care Rehabilitation Program in pediatric asthma. *Health Educ Q* 1985; 12:333-342.
15. Evans D, Clark NM, Feldman CH, Rips J, Kaplan D, Levison MJ et al. A school health education program for children with asthma aged 8-11 years. *Health Educ Q* 1987; 14:267-279.
16. Snyder SE, Winder JA, Creer TJ. Development and evaluation of an adult asthma self-management program: Wheezers Anonymous. *J Asthma* 1987; 24:153-158.
17. Beasley R, Cushley M, Holgate ST. A self management plan in the treatment of adult asthma. *Thorax* 1989; 44:200-204.
18. Abramson MJ, Baily MJ, Couper FJ, Driver JS, Drummer OH, Forbes AB et al. Are asthma medications and management related to deaths from asthma. *Am J Respir Crit Care Med* 2001; 163:12-18.
19. Abdulwadud OA, Abramson MJ, Light L, Thien FC, Walters EH. Comparison of patients with asthma managed in general practice and in a hospital clinic [see comments]. *Med J Aust* 1999; 171(2):72-75.
20. Hoskins G, Neville RG, Smith B, Clark RA. Do self-management plans reduce morbidity in patients with asthma? *British Journal of General Practice* 1996; 46:169-171.
21. Jones KP, Mullee MA, Middleton M, Chapman E, Holgate ST. Peak flow based asthma self-management: a randomised controlled study in general practice. British Thoracic Society Research Committee. *Thorax* 1995; 50:851-857.
22. Partridge MR. Delivering optimal care to the person with asthma: what are the key components and what do we mean by patient education? *Eur Respir J* 1995; 8:298-305.
23. Cochrane GM. Compliance and outcomes in patients with asthma. *DRUGS* 1996; 52 Supplement:12-19.
24. Gibson PG, Hensley MJ, Abramson M, Bauman A, Walters EH. Limited (information only) patient education programs for adults with asthma (Cochrane Review). *Cochrane Library* [2]. 2001. Oxford: Update Software.
25. Thoonen BPA, Schermer TRJ, Schayck CPv. Self-managed asthma education diminishes the risk of underestimating information needs of asthma patients. *Prim Care Respir J* 2000; 9(2):39-39.

26. anonymous. Global strategy for asthma management and prevention
NHLBI/WHO workshop report. 95-3659. 1995. National heart, lung and blood institute. The cited workshop-report is published by National Institutes of Health: Bethesda (Maryland)
27. Charlton I, Charlton G, Broomfield J, Mullee MA. Evaluation of peak flow and symptoms only self management plans for control of asthma in general practice [see comments]. *BMJ* 1990; 301:1355-1359.
28. Turner MO, Taylor D, Bennett R, FitzGerald JM. A randomized trial comparing peak expiratory flow and symptom self-management plans for patients with asthma attending a primary care clinic. *Am J Respir Crit Care Med* 1998; 157(2):540-546.
29. Partridge MR, Hill SR. Enhancing care for people with asthma: the role of communication, education, training and self-management. 1998 World Asthma Meeting Education and Delivery of Care Working Group. *Eur Respir J* 2000;16:333-348.
30. Bailey WC, Richards JM, Jr., Brooks CM, Soong SJ, Windsor RA, Manzella BA. A randomized trial to improve self-management practices of adults with asthma. *Arch Intern Med* 1990; 150:1664-1668.
31. D'Souza W, Crane J, Burgess C, Te Karu H, Fox C, Harper M et al. Community-based asthma care: trial of a "credit card" asthma self-management plan. *Eur Respir J* 1994; 7:1260-1265.
32. Allen RM, Jones MP, Oldenburg B. Randomised trial of an asthma self-management programme for adults. *Thorax* 1995; 50:731-738.
33. Ignacio Garcia JM, Gonzalez Santos P. Asthma self-management education program by home monitoring of peak expiratory flow. *Am J Respir Crit Care Med* 1995; 151:353-359.
34. Kotses H, Bernstein IL, Bernstein DI, Reynolds RV, Korbee L, Wigal JK et al. A self-management program for adult asthma. Part I: Development and evaluation. *J Allergy Clin Immunol* 1995; 95:529-540.
35. Taitel MS, Kotses H, Bernstein IL, Bernstein DI, Creer TL. A self-management program for adult asthma. Part II: Cost- benefit analysis. *J Allergy Clin Immunol* 1995; 95:672-676.
36. Ayres JG, Campbell LM. A controlled assessment of an asthma self-management plan involving a budesonide dose regimen. *OPTIONS Research Group. Eur Respir J* 1996; 9(5):886-892.
37. Lahdensuo A, Haahtela T, Herrala J, Kava T, Kiviranta K, Kuusisto P et al. Randomised comparison of cost effectiveness of guided self management and traditional treatment of asthma in Finland. *BMJ* 1998; 316:1138-1139.

38. Kauppinen R, Sintonen H, Vilkkä V, Tukiainen H. Long-term (3-year) economic evaluation of intensive patient education for self-management during the first year in new asthmatics. *Resp Med* 1999;93:283-289.
39. Klein JJ, van der Palen J, Uil SM, Zielhuis GA, Seydel ER, van Herwaarden CLA. Benefit from the inclusion of self-treatment guidelines to a self-management programme for adults with asthma. *Eur Respir J* 2001;17:386-394.

Chapter 10

General discussion

Aim and main results

Main goal of the ZBA-study was to study to what extent self-management based on patient education, skills training and a written self-treatment plan results in more effective and efficient management of asthma with inhaled corticosteroids in general practice. Main findings from this study are:

1. Self-management of asthma provides a safe basis for intermittent therapy with inhaled corticosteroids.
2. Self-management lowers the burden of illness as perceived by patients and is at least equally effective in controlling asthma than conventional care.
3. When the indirect costs are included, guided self-management is at least equally, but probably more efficient than conventional care when both are provided by GPs.
4. Using materials for systematically taking into account the patients' needs may enhance shared decision-making by balancing the patients' and the GP's perspective in a more patient centered approach.
5. When educating asthma patients an important role of the GP is to increase the patients awareness of issues possibly relevant for their asthma.
6. Patients using low or intermediate dosages of inhaled steroids are predominantly treated in general practice. The acceptance-rate of guided self-management plans by patients in this category is sufficiently high to justify implementation of self-management of asthma in general practice.
7. The acceptance-rate of self-treatment of asthma by GPs does not seem to be an obstacle for the implementation of such programmes.
8. Both local and international evidence about benefits and applicability of self-management justify a broader recommendation of self-management in the Dutch guidelines on the treatment of asthma in general practice.

External validity

Findings from this study provide important data on the applicability of self-management in Dutch general practice. These findings are based on a sample of patients treated in general practice. Based on the initial dose of inhaled corticosteroids and the number of asthma attacks in the previous months patients

included in the ZBA study represent asthma patients with mild to moderate persistent asthma, which are predominantly treated at step 2 of the GINA-guidelines and the Dutch guidelines.

In our study asthma appears to be well controlled in terms of baseline FEV₁ level and reversibility. However initial asthma control must be interpreted with caution. First of all patients with a smoking history of 15 packyears or more were excluded from the study. This was intended to reduce the risk of including patients with COPD, but may also have excluded a group of relatively poor controlled asthma patients. Moreover patients with a pre-bronchodilator FEV₁ less than 80% of predicted at the start of the study were pre-treated with 800 mcg budesonide twice daily during a six weeks run in period. Interpreting asthma control in these groups based on baseline FEV₁ or FEV₁-reversibility may give an overestimation of control as 23-35% required such pre-treatment (see chapters 6 and 7). This means that findings from our study are not externally valid per se: the results pertain to asthma patients with mild to moderate persistent asthma, provided that the initial step in providing asthma self-management is optimisation of asthma control by the GP.

Room for improvement

As stated in the introduction emergency room visits and hospitalisations are relatively rare in asthma patients with mild to moderate persistent asthma, which is confirmed in chapter 7. In literature beneficial effects of self-management were mostly demonstrated in outpatient clinics and emergency room departments. Here self-management programs are capable of reducing hospital admissions and emergency room visits. Days off work can be reduced and quality of life is improved¹⁻¹². One recent study by Abramson et al even demonstrated a reduction in asthma mortality¹³. In these settings asthma patients tend to have more severe asthma, leaving more room for improvement. Furthermore pulmonary departments often have the advantage of having specially trained personnel available. Findings in these settings can not be generalised on beforehand to general practice, where loss of asthma control occurs less frequently and there is lower impact on quality of life¹⁴. Thus far there are few randomised controlled trials to the effects of guided self-management programs in family practice. Hoskins et al showed reductions in morbidity in terms of

hospital admission, (emergency) consultations, oral steroid courses and emergency nebulisations. But due to possible selection bias superiority of self-management plans could not be proven¹⁵. Their results suggest that improvements in clinical and morbidity parameters are indeed less likely to occur in mild asthmatics. Jones et al also concluded this, but they may have failed to show results due to the small number of subjects¹⁶. In the light of this limited room for (clinical) improvement our hypothesis was that self-management of asthma had to be at least equally effective as usual care in order to provide an acceptable alternative. The additional value of self-management is the change to patients fully sharing responsibility of treatment with their caregivers (Chapter 8) based on a common frame of reference (Chapter 9). This makes self-management of asthma an attractive strategy for enhancing patient autonomy. In addition to effects on lung function and costs, effects on patient-related parameters come in scope and have been taken into account in this thesis.

Interpretation of results

In chapter 6 of this thesis effects of self-management on asthma-control, quality of life, medication use and indicators of exacerbations have been studied in a randomised controlled trial in a general practice population. There were no statistically significant differences in the annual FEV₁ decline-rate and no between-group differences in FEV₁-reversibility and PC₂₀-histamine. In the self-management group asthma control improved in terms of a higher number of successfully treated weeks. This was associated with moderate improvements in quality of life. There was a clinically relevant improvement in the emotions domain. This indicates that patients in the self-management group felt less worried or insecure about the influence of their asthma on daily life. General practitioners did not diagnose more exacerbations, but the number of oral prednisolone courses was higher in the guided self-management group. As described in chapter 6 this finding may have been the consequence of either registration bias, a baseline difference in asthma control or an effect of the self-management program itself.

In the ZBA-project cost data were studied too. The economic consequences of our self-management program are described in chapter 7. In terms of quality of life and

successfully treated weeks self-management of asthma appears to be a dominant treatment strategy in comparison to usual care (i.e. better outcomes at less cost). But statistics in chapter 7 show that this may be entirely due to chance. From a societal perspective guided self-management is at least equally, but probably more efficient than conventional care when both are provided by GPs.

As stated earlier in this discussion, patient-related outcomes also provide information about the usefulness of our self-management program. In chapter 5 we studied if patient-centered education was able to reduce information needs of patients in a satisfactory way. The use of a structured education program (appendix I) to support the GP and a feedback tool to support the patient (appendix II) resulted in a significant reduction of information needs of patients. Patient satisfaction increased, especially in items related to asthma management. These findings are consistent with the reduction in lost-activity days and the higher number of successfully treated weeks. Not only does this reduce the burden of illness as perceived by patients, but is also results in a reduction of disease related costs. The observed patient-related outcomes and their economic consequences are the outcomes in which self-management of asthma distinguishes itself from usual asthma care, even under conditions where room for improvement initially seemed limited.

Determinants of success

Participating practices

First of all GPs involved in this study were all in favour of self-management and had a positive attitude towards scientific research. It is therefore likely that they were highly motivated and have put a maximum effort in implementing the experimental self-management program. The finding that none of the GPs has dropped out due to loss of motivation illustrates this. All participating GPs were trained before implementing self management. Main goal of this training program was to provide a standardised self-management intervention. As is described in chapter 7 the intracuster correlation for practices was insignificantly low. These findings do support our hypothesis that the self-management program can be implemented in a standardised manner by GPs. It makes self-management of asthma a valuable

management strategy, regardless of differences in organisation or size of general practices.

Participating patients

As is demonstrated in chapter 5 and 6 a large number of patients has been invited to participate in the study. At least half of all invited patients refused to participate or did not respond to the invitation of their GP. Based on available data we concluded that the dosage of inhaled steroids is associated with willingness to participate. As is stated in chapter 4 this may have resulted in losing a group of patients that might have profited from self-management, resulting in a reduction in room for improvement and smaller effects. Willingness to participate was also relatively low in patients using higher daily dosages of inhaled corticosteroids. These patients may very well be the ones that were unable to reduce their dosage of inhaled corticosteroids in the past. So patients finally included in the study may have had positive experiences with stopping inhaled corticosteroids in the past. Patients included in the study thus may have been those patients in which intermittent therapy with inhaled steroids was possible on beforehand. The informed consent procedure may also have contributed to this selection. Patients were informed about the treatment strategy they were going to have during the study. Patients in the self-management group were informed about the possibility of reducing or temporarily stopping inhaled corticosteroids. Their decision to participate in the study is more likely to be influenced by earlier experiences with (temporarily) stopping than for patients in the usual care group. This may explain the difference in willingness to participate between usual care and self-management (chapters 6 and 7). Based on our findings it cannot be concluded that intermittent treatment with inhaled steroids is feasible or effective for all asthma patients in general practice. On the other hand there is no harm in trying to reduce the dosage of inhaled medication. It is in accordance with recommendations in asthma management guidelines. The selection procedure presented in chapter 4 can be helpful to identify those patients that can reduce or stop inhaled steroids through self-management and those who need assistance of the GP first.

The self-management program studied in this thesis consisted of three elements: patient education, skills training and a written self-treatment plan. Examining effects of our self-management program as a whole in a randomised controlled trial has the potential disadvantage of being unable to discriminate which of the program contents attributes to the final effects. We deliberately choose to examine this 'black box' as a whole for several reasons. First of all the effects of the individual components (e.g. training of peak flow measurement and educating patients) is limited or absent. Based on current insights, integration of education, skills training and a written self-treatment plan has the greatest potential of being effective. This approach has been acknowledged in two Cochrane reviews, published by Gibson et al.^{17;18}. Choosing this integrated approach also has a pragmatic background. Handing out written guidelines for treatment adjustment based on peak-flow measurements and self-assessment of asthma symptoms is likely to fail on beforehand if patients are unable to measure their own peak-flow and are unaware of the relevance of symptoms monitored.

Based upon our study-design we can only conclude that a combined self-management program is beneficial and feasible in General Practice. It is still unclear which parts of the self-management program are the most effective and if there is a cumulative effect or synergism. Further clarification of the coherence of the program contents and the possibility of eliminating redundant or ineffective components may increase efficiency and cost-effectiveness of the program.

Considerations for daily practice

The essentials of the self-management program are more active involvement of patients through patient centered education and use of a self-treatment plan aiming at dose adjustment of inhaled steroids according to self-assessed levels of asthma control.

In this thesis it is demonstrated that patient education, training of inhalation technique, peak flow measurement and written self-treatment guidelines applied in an integrated patient-centered approach are effective in terms of symptom reduction, reduction of lost activity days, reduction of inhaled corticosteroids and

improved quality of life. In our self-management program components of asthma management are incorporated in a coherent patient centered framework. As is demonstrated in chapter 7 self-management of asthma based on these elements is a more efficient treatment strategy than usual care from a health policy perspective. But these findings also confirm that implementation of self management is time and resource consuming. Time spent by GPs to educate and train patients was the main implementation expenditure. As this was identified as a possible barrier for implementation by GPs (chapter 3), this problem will need further attention when implementing self-management in general practice. Especially as GPs themselves will probably not directly notice the benefits resulting from their efforts. In the light of our findings several alternatives can be considered. First of all the introduction of nurse practitioners in Dutch general practice provides new opportunities. Educational tasks and skills training can be easily delegated to these health professionals and the gains are obvious. Nurse practitioners in general have more available time per patient at lower cost and have often better educational skills than GPs. Another more time efficient option is group wise patient education. Such an education strategy passes by individual information needs of patients and can as such be less patient-centered. However, data presented in chapter 5 demonstrate a substantial number of items that is of interest for most patients and some information items can be identified as obligatory knowledge for all patients. The latter was characterised as 'need to know' in chapter 5. Such items can easily be presented in group wise education sessions. Additionally the information checklist for patients can be used in individual GP-patients contacts to identify and discuss specific individual needs. As is shown in chapter 5 using such a checklist for systematically taking into account the patients' needs may enhance shared decision-making by balancing the patients' and the GP's perspective in a more patient centered approach¹⁹.

Another third party that might be involved in providing self-management care is the occupational health physician. Reduction in lost-activity days is one of the main benefits of our self-management program. We did not measure the effect of the self-management program on *reduced*-activity days. It is a known fact that patients often underestimate the relation between asthma and non-specific complaints like fatigue

and headache. Such complaints may lead to a reduction in quality of life, daily activities and productivity. Increasing the awareness of patients about these phenomena and teaching them to take appropriate action may further improve quality of life and reduce the perceived burden of illness. Occupational health physicians often have a good view on activity reducing factors and are able to elucidate unknown triggers in the work environment. As is discussed in chapter 7 patients demonstrated high adherence in the area of healthy behaviour, so additional efforts in this area are likely to be beneficial.

Finally willingness of GPs to start using self management of asthma needs to be addressed. Based on findings presented in chapter 4 the acceptance-rate of self-management among GPs is sufficiently high, but there also is a substantial group that has doubts about the usefulness of self-management. Findings from our study may be helpful in changing these doubts. Ninety (90) percent of GPs who reported self-management to be useful is willing to apply this to their patients. Taking away doubts about the usefulness of selfmanagement thus is likely to increase the acceptance of self management in Dutch general practice.

Recommendations and further research

Based on our findings we conclude that our self-management program has been successful and we recommend implementation of this treatment strategy in Dutch general practice. Both local and international evidence about benefits and applicability of self management justify a broader recommendation of self-management in the Dutch guidelines on the treatment of asthma in general practice. The introduction of self-management in Dutch general practice should not aim at replacing current management strategies. It is an at least equal alternative and provides a safe strategy when intermittent treatment with inhaled corticosteroids is required for whatever reason. The current recommendation in Dutch guidelines that asthma self-management should be at least for patients with severe asthma or frequent loss of asthma control or hospitalisations should be extended to patients with mild or moderately severe asthma. The decision model presented in chapter 4 can be used for identification and assessment of asthma patients that are interested in self-management.

Further research is needed to elucidate if additional criteria or patient characteristics can be helpful in identifying or selecting those patients that will benefit most from self management. In addition possible improvements in the self-management program in terms of removing ineffective and redundant elements requires further attention. Part of the beneficial effects found in this study may be the consequence of following a well-described and controlled program. Consequently questions arise in which way patients will continue using their self-treatment program and to what extent the effects found remain or change in the long term.

Rearranging the organisation and delivery of asthma care into a mode of co-operation aiming at shared responsibilities and patient-centeredness has to some extent shown to be effective in narrowing the gap between efficacy and effectiveness of asthma care. Finding the answer to the still unanswered research questions mentioned above is no prerequisite for the introduction of self-management in Dutch General Practice, it can only optimise it.

References

1. Bailey WC, Richards JM, Jr., Brooks CM, Soong SJ, Windsor RA, Manzella BA. A randomized trial to improve self-management practices of adults with asthma. *Arch Intern Med* 1990; 150:1664-1668.
2. Charlton I, Charlton G, Broomfield J, Mullee MA. Evaluation of peak flow and symptoms only self management plans for control of asthma in general practice [see comments]. *BMJ* 1990; 301:1355-1359.
3. D'Souza W, Crane J, Burgess C, Te Karu H, Fox C, Harper M et al. Community-based asthma care: trial of a "credit card" asthma self-management plan. *Eur Respir J* 1994; 7:1260-1265.
4. Allen RM, Jones MP, Oldenburg B. Randomised trial of an asthma self-management programme for adults. *Thorax* 1995; 50:731-738.
5. Boulet LP, Boutin H, Cote J, LeBlanc P, Laviolette M. Evaluation of an asthma self-management education program. *J Asthma* 1995; 32(3):199-206.
6. Ignacio Garcia JM, Gonzalez Santos P. Asthma self-management education program by home monitoring of peak expiratory flow. *Am J Respir Crit Care Med* 1995; 151:353-359.
7. Kotses H, Bernstein IL, Bernstein DI, Reynolds RV, Korbee L, Wigal JK et al. A self-management program for adult asthma. Part I: Development and evaluation. *J Allergy Clin Immunol* 1995; 95:529-540.
8. Taitel MS, Kotses H, Bernstein IL, Bernstein DI, Creer TL. A self-management program for adult asthma. Part II: Cost- benefit analysis. *J Allergy Clin Immunol* 1995; 95:672-676.
9. Ayres JG, Campbell LM. A controlled assessment of an asthma self-management plan involving a budesonide dose regimen. *OPTIONS Research Group. Eur Respir J* 1996; 9(5):886-892.
10. Meijer RJ, Kerstjens HA, Postma DS. Comparison of guidelines and self management plans in asthma. *Eur Resp J* 1997; 10(5):1163-1172.
11. Lahdensuo A, Haahtela T, Herrala J, Kava T, Kiviranta K, Kuusisto P et al. Randomised comparison of cost effectiveness of guided self management and traditional treatment of asthma in Finland. *BMJ* 1998; 316:1138-1139.
12. Kauppinen R, Sintonen H, Vilkkä V, Tukiainen H. Long-term (3-year) economic evaluation of intensive patient education for self-management during the first year in new asthmatics. *Resp Med* 1999; 93: 283-289.

13. Abramson MJ, Baily MJ, Couper FJ, Driver JS, Drummer OH, Forbes AB et al. Are asthma medications and management related to deaths from asthma. *Am J Respir Crit Care Med* 2001; 163:12-18.
14. Abdulwadud OA, Abramson MJ, Light L, Thien FC, Walters EH. Comparison of patients with asthma managed in general practice and in a hospital clinic [see comments]. *Med J Aust* 1999; 171(2).72-75.
15. Hoskins G, Neville RG, Smith B, Clark RA. Do self-management plans reduce morbidity in patients with asthma? *British Journal of General Practice* 1996; 46:169-171.
16. Jones KP, Mullee MA, Middleton M, Chapman E, Holgate ST. Peak flow based asthma self-management: a randomised controlled study in general practice. *British Thoracic Society Research Committee. Thorax* 1995; 50:851-857.
17. Gibson PG, Hensley MJ, Abramson M, Bauman A, Walters EH. Limited (information only) patient education programs for adults with asthma (Cochrane Review). *Cochrane Library* [2]. 2001. Oxford: Update Software.
18. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ et al. Self-management education and regular practitioner review for adults with asthma (Cochrane Review). *The Cochrane Library Issue 3*. 2000. Oxford: Update Software.
19. Fay JK, Jones A. Guided self management of asthma. More information is needed on what patients think about such management. *BMJ* 2000; 320(7229):249.

Chapter 11

Summary (in Dutch) - Samenvatting

Hoofdstuk 1: inleiding

De afgelopen decennia is het begrip over astma sterk toegenomen. Het inzicht dat chronische ontsteking van de bronchiaalboom het belangrijkste onderliggende mechanisme in de pathofysiologie van astma is, heeft geleid tot een brede acceptatie van inhalatiecorticosteroiden als hoeksteen van de medicamenteuze behandeling van astma. Hierdoor is ernstige astmagerelateerde morbiditeit voor veel astmapatiënten tot nul gereduceerd. Er is echter nog steeds veel ruimte voor verbetering. Astma is vaak minder goed onder controle dan de patiënt zelf denkt en er is nog steeds een aanzienlijk verlies van activiteiten en productiviteit als gevolg van astma. Veelal wordt gebrekkige therapietrouw als verantwoordelijke factor aangewezen. Hier staat tegenover dat het alsmat harder aanmoedigen van therapietrouw niet tot aantoonbaar betere resultaten leidt. Ook is nog onduidelijk of een continue behandeling met inhalatiecorticosteroiden wel voor alle patiënten noodzakelijk is. Er zijn aanwijzingen dat inhalatiecorticosteroiden in veel gevallen intermitterend gebruikt kunnen worden of in ieder geval gereduceerd kunnen worden tot een minimale effectieve dosering. De uitdaging is het vinden van de optimale balans tussen overbehandeling en onderbehandeling. In dit proefschrift wordt beschreven in hoeverre individuele aanpassing van de behandeling door middel van zelfmanagement een veilig, efficiënt en kosteneffectief antwoord op deze uitdaging is. Het zelfmanagementprogramma dat is onderzocht (ZBA-project) rust op drie belangrijke pijlers: patiëntenvoorlichting, training van benodigde vaardigheden en een geschreven richtlijn voor zelfstandige aanpassing van de onderhoudsbehandeling met inhalatiecorticosteroiden.

Hoofdstuk 2: de plaats van zelfmanagement

In 1998 werd op het WONCA-wereldcongres een symposium gehouden over de toenmalige stand van zaken met betrekking tot de behandeling van astma en COPD. Nieuwe behandelingen en behandelstrategieën werden gepresenteerd. Therapietrouw werd erkend als een belangrijke beperkende factor voor de effectiviteit van nieuwe en bestaande therapieën. Zelfmanagement werd gepresenteerd als een patiënt-georiënteerd antwoord op dit probleem. Door grotere betrokkenheid en een duidelijkere eigen verantwoordelijkheid van de patiënt kunnen

belangen van patiënt en huisarts beter met elkaar in overeenstemming worden gebracht. Het belang van onderzoek naar de bruikbaarheid van dit concept werd expliciet onderkend door de deelnemers.

Hoofdstuk 3: verwachtingen en ervaringen van huisartsen

Om inzicht te krijgen in de specifieke eisen die het introduceren van zelfmanagement in de huisartspraktijk stelt aan de huisarts en aan de huisartspraktijk werd een onderzoek gedaan in een steekproef uit Britse en Nederlandse huisartsen. De eerste groep vanwege de reeds aanwezige ervaringen bij het toepassen van zelfmanagement, de tweede groep om verwachtingen en mogelijke barrières te inventariseren. De bereidheid om zelfbehandeling te gaan toepassen in de eigen praktijk was onder de totale groep van 287 geënquêteerde huisartsen 51% en dit liep op tot 90% onder de huisartsen die zelfmanagement als bruikbaar inschatten (75% van alle geënquêteerde huisartsen). Nederlandse huisartsen staan in het algemeen welwillend tegenover de invoering van zelfbehandeling, maar niet voordat er een aangetoonde meerwaarde is. Door de Nederlandse huisartsen werden vooral problemen verwacht op het gebied van beschikbare tijd, benodigde materialen en de hieraan gerelateerde kosten. Deze verwachtingen bleken goed overeen te komen met de ervaringen van de Britse collega's. Op basis van de bevindingen uit dit onderzoek kan geconcludeerd worden dat er een aantal herkenbare drempels bestaan voor de invoering van zelfmanagement. Ondanks de aanwezigheid van deze drempels is er voldoende draagvlak voor invoering van zelfmanagement in de Nederlandse huisartspraktijk.

Hoofdstuk 4: bereidheid tot deelname van patiënten

Op grond van argumenten als aversie en angst voor de bijwerkingen van inhalatiecorticosteroïden is het ogenschijnlijk logisch dat patiënten geïnteresseerd zijn in de mogelijkheid om hun onderhoudsbehandeling af te bouwen of te stoppen. Patiënten die baat hebben bij een onderhoudsbehandeling met inhalatiecorticosteroïden zijn anderzijds mogelijk huiverig om deze te stoppen als dit tot ongewenst controleverlies leidt. In hoofdstuk 4 wordt een studie beschreven naar de mogelijke rol die inhalatiecorticosteroïden spelen bij de bereidheid van patiënten

om zelfmanagement toe te gaan passen. Op grond van eerdere observaties werd daarnaast gekeken naar de rol van geslacht, leeftijd en de beroepsstatus. Van de 283 onderzochte patiënten bleek 52% interesse te hebben in deelname aan een zelfmanagement programma. In de onderzochte groep kon geen duidelijke associatie tussen leeftijd en geslacht en de bereidheid tot deelname worden aangetoond. Patiënten zonder werk of studie hadden een relatief hoge bereidheid tot deelname. Dit gegeven bleek echter bij de huisarts vaak niet goed bekend. Op grond van deze bevindingen is het daarom niet mogelijk een algemene conclusie te trekken met betrekking tot de rol van de beroepsstatus en de bereidheid tot deelname aan een zelfmanagementprogramma.

Er was een statistisch significante en onafhankelijke associatie tussen de bereidheid tot deelname en de hoeveelheid inhalatiecorticosteroiden die patiënten gebruikten. Patiënten die geen inhalatiecorticosteroiden gebruikten (terwijl ze dit op grond van selectie door de huisarts wel zouden moeten), hadden de laagste bereidheid tot deelname (43 van de 143, 30%). Ten opzichte van deze eerste groep hadden patiënten met lage doseringen inhalatiecorticosteroiden de hoogste bereidheid tot deelname (OR 10.59, 95% betrouwbaarheidsinterval 4.70-23.88). De bereidheid tot deelname nam af met de hoogte van de dosering inhalatiecorticosteroiden en was in de groep met de hoogste dosering inhalatiecorticosteroiden 18% (OR 3.06, 95% betrouwbaarheidsinterval 1.33 – 7.04). Op grond van deze bevindingen kan de huisarts gerichter zelfmanagement aanbieden aan astmapatiënten. Bij patiënten die geen inhalatiecorticosteroiden gebruiken, terwijl dit wel gewenst is, kan eerst het starten van een onderhoudsbehandeling en de therapietrouw worden besproken. Bij patiënten met relatief hoge doseringen inhalatiecorticosteroiden is het raadzaam om gezamenlijk de mogelijkheden voor dosisverlaging te exploreren. Pas als patiënt en huisarts ervaren hebben dat dit niet gepaard gaat met ongewenst controleverlies, kan de mogelijkheid om zelfstandig de onderhoudsbehandeling te variëren worden aangeboden. Astmapatiënten met een lage tot gemiddelde dosering inhalatiecorticosteroiden zijn zeer waarschijnlijk op voorhand bereid tot deelname aan zelfmanagement.

Hoofdstuk 5: de patiënt centraal

Kerngedachte van het zelfmanagementprogramma is het delen van verantwoordelijkheden tussen huisarts en patiënt. De patiënt wordt meer nadrukkelijk verantwoordelijk voor het nemen van beslissingen met betrekking tot de dagelijkse omgang met astma. Hierbij staan thema's als het vermijden van uitlokkende factoren en een bewust gebruik van de verschillende astmamedicijnen centraal. De huisarts heeft in dit model de verantwoordelijkheid om de patiënt te voorzien van de benodigde kennis en vaardigheden om dergelijke beslissingen weloverwogen te kunnen nemen. Hierbij kan onderscheid gemaakt worden tussen astmagerelateerde informatie waarover de patiënt volgens de arts zou moeten beschikken en informatie waar de patiënt zelf behoefte aan heeft; 'willen weten' versus 'moeten weten'. Om deze discrepantie in de belangen van patiënt en huisarts te overbruggen, is gekozen voor een meer patiëntgerichte benadering. Door middel van het gebruik van gestructureerde feedback krijgen patiënten meer invloed op de inhoud van voorlichting en training die door hun huisarts gegeven wordt. In hoofdstuk 5 wordt onderzocht of en hoe het zelfmanagementprogramma aansluit op de informatiebehoefte van astmapatiënten en of dit ook leidt tot grotere tevredenheid. Voorlichting en instructie in het kader van het zelfmanagementprogramma werden gegeven in vier consulten over een periode van drie maanden. Vlak voor ieder voorlichtingsconsult werd door patiënten (n=98) een checklist ingevuld. Met behulp van deze checklist konden patiënten uit het totale aanbod van informatie over astma aangeven waarover ze zelf vragen hadden. Tijdens de voorlichtingsconsulten werd door de huisarts systematisch de informatiebehoefte van patiënten geïnventariseerd aan de hand van de checklist. Deze aanpak bleek te leiden tot een forse daling in de informatiebehoefte van astmapatiënten. Deze patiënten waren meer tevreden over de zorg van hun huisarts dan een controlegroep van 95 patiënten die gedurende dezelfde periode de 'gewone' astmazorg van hun huisarts ontvingen. Patiënten uit de zelfmanagementgroep oordeelden met name positief over de aandacht van hun huisarts voor de persoonlijke gevolgen van astma en de ondersteuning van de huisarts in het zelfstandig omgaan met astma.

Op grond van deze bevindingen kan geconcludeerd worden dat het zeer wel mogelijk is om gericht rekening te houden met wensen van patiënten, zonder daarbij te kort te doen aan de strikt medische belangen. Dit leidt tot meer betrokken en gemotiveerde patiënten. Het op een dergelijke manier delen van verantwoordelijkheden is dan ook een belangrijke voorwaarde voor de effectiviteit van zelfmanagement.

Hoofdstuk 6: klinische effectiviteit van zelfmanagement

In dit hoofdstuk wordt een gerandomiseerde gecontroleerde studie beschreven naar het effect van zelfmanagement op astmacontrole, kwaliteit van leven en de invloed van astma op het dagelijks functioneren. In deze studie werden 19 huisartspraktijken met in totaal 49 huisartsen willekeurig verdeeld over twee groepen: zelfmanagement en reguliere astmazorg. Astmapatiënten werden daarna door hun huisarts uitgenodigd om mee te doen aan het onderzoek. Op een longfunctielaboratorium werd gecontroleerd of geïnteresseerde patiënten voldeden aan alle criteria voor deelname. Uiteindelijk konden 214 patiënten aan de studie mee doen, waarvan 110 in de zelfmanagement groep. Patiënten in de reguliere zorggroep kregen dezelfde astmazorg van hun huisarts als voor het onderzoek, dat wil zeggen de zorg zoals deze is omschreven in de richtlijn voor de behandeling van astma van het Nederlands Huisartsen Genootschap. Het zelfmanagementprogramma bestond uit patiëntgeoriënteerde voorlichting over astma, training van de piekstroommeting, periodieke controle en instructie van de inhalatietechniek en een geschreven richtlijn voor zelfbehandeling met inhalatiecorticosteroiden. Met behulp van deze richtlijn konden patiënten aan de hand van zelf gemeten piekstroomwaarden en alarmsymptomen zelfstandig de ontstekingsremmende behandeling bijstellen, variërend van volledig stoppen met inhalatiecorticosteroiden tot en met het zelfstandig starten van een prednison stootkuur.

Alle patiënten bezochten gedurende twee jaar ieder half jaar het longfunctielaboratorium voor meting van onder andere de longfunctie en de astmagerelateerde kwaliteit van leven. Daarnaast werd door de patiënt wekelijks een rapportage bijgehouden van de mate van kortademigheid en het aantal dagen waarop de dagelijkse activiteiten moesten worden verzuimd als gevolg van astma.

Alle weken waarbij de kortademigheid onder een individueel bepaald acceptabel niveau bleef, werden geteld als succesvol behandelde weken. Aan het eind van de studie waren er gemiddeld 81 (95% betrouwbaarheidsinterval 78-84) succesvol behandelde weken per patiënt in de zelfmanagementgroep en 75 (95% betrouwbaarheidsinterval 72-78) in de groep die reguliere astmazorg ontving. Een belangrijke bevinding bleek het verschil in het aantal dagen waarop patiënten als gevolg van astma hun reguliere activiteiten moesten verzuimen. In de zelfmanagementgroep was dit verzuim gemiddeld per patiënt 1.2 dagen (95% betrouwbaarheidsinterval 0.5-1.9), tegen 3.9 dagen (95% betrouwbaarheidsinterval 2.5-5.4) in de groep die reguliere zorg ontving. Deze bevindingen werden weerspiegeld in de gemeten kwaliteit van leven in beide groepen. In de loop van beide onderzoeksjaren was de toename van kwaliteit van leven in de zelfmanagementgroep groter dan de toename in de groep die reguliere astmazorg ontving ($p=0.055$). Dit verschil in toename bleek met name verklaard te kunnen worden doordat er in de zelfmanagementgroep meer patiënten waren die minder angstig of bezorgd waren over de invloed van astma op hun dagelijks leven. Gemeten over twee jaar was er noch een verschil in het verloop van de longfunctie tussen beide groepen, noch in de het gebruik van luchtwegverwijders. Daarnaast bleek er een statistisch significante, besparing in het totaal aantal gebruikte inhalatiecorticosteroiden te zijn van 217 inhalaties, ten gunste van de zelfmanagementgroep. Geconcludeerd kan worden dat zelfmanagement een verantwoorde methode is voor intermitterende behandeling met inhalatiecorticosteroiden. De belangrijkste winst van zelfmanagement is de reductie van de door de patiënt ervaren hinder en symptomen.

Hoofdstuk 7: kosten-effectiviteit van zelfmanagement

In het ZBA-project zijn gegevens verzameld over kosten die in verband met, of als gevolg van astma gemaakt zijn. Ook werden, naast de metingen die zijn beschreven in hoofdstuk 6, op basis van de halfjaarlijkse metingen op het longfunctielaboratorium QALY's (Quality Adjusted Life Years) berekend. Met behulp van de uitkomstmaten uit hoofdstuk 6, de gemeten kosten en de QALY's wordt in hoofdstuk 7 beschreven hoe kosten en effecten bij astma zelfmanagement zich

verhouden tot kosten en effecten bij reguliere zorg. Een belangrijke bron van kosten zijn de kosten om het zelfmanagementprogramma in de huisartspraktijk te kunnen introduceren. Deze zogenaamde implementatiekosten bedroegen € 189 per patiënt. De belangrijkste kostenbronnen in relatie tot astmazorg waren astmamedicatie (met name budesonide), maatregelen gericht op allergeenreductie, huisartscontacten en verlies van productiviteit (bijvoorbeeld door arbeidsverzuim). De kosten voor budesonidegebruik en kortwerkende luchtwegverwijders waren significant lager voor zelfmanagement, met een besparing van € 75 per patiënt per twee jaar. In de zelfmanagementgroep werden opvallend vaker saneringsmaatregelen getroffen dan in de reguliere zorggroep (relatief risico = 1.7, 95% betrouwbaarheidsinterval 1.3-2.2). Dit leidde tot een kostentoename van gemiddeld € 84 per patiënt. Zoals in hoofdstuk 6 beschreven, was het verlies van productiviteit in de zelfmanagementgroep significant lager dan in de reguliere zorggroep. Vertaald in de hieraan gerelateerde kosten leverde het zelfmanagementprogramma hierdoor een besparing op van € 213 per patiënt per twee jaar. De besparingen in deze kostencategorie bleken in het tweede jaar van de studie relatief groter dan in het eerste jaar. Na optelling van alle kosten (inclusief implementatiekosten) bedroegen de kosten per patiënt per twee jaar bij zelfmanagement van astma € 1084 (95% betrouwbaarheidsinterval 948-1228) en voor de reguliere astmazorg € 1097 (95% betrouwbaarheidsinterval 933-1260). Dit betekent dus dat zelfmanagement na twee jaar neutraal in kosten is in vergelijking met reguliere zorg, ondanks de implementatiekosten en het toegenomen aantal saneringsmaatregelen. Als de gevonden besparingen na twee jaar blijven bestaan of groter worden, zal zelfmanagement op termijn dus efficiënter zijn.

Naast een vergelijking van kosten en besparingen wordt in hoofdstuk 7 ook een kosten-effectiviteitsanalyse beschreven. Met betrekking tot QALY's, aantal succesvol behandelde weken en het aantal patiënten met een relevante toename van de kwaliteit van leven lijkt het zelfmanagementprogramma dominant te zijn. Dat wil zeggen dat met zelfmanagement tegen lagere kosten méér effect op deze uitkomsten bereikt wordt. De stelligheid waarmee deze conclusie getrokken kan worden is echter beperkt als gevolg van een grote mate van spreiding in de bevindingen. Vanuit gezondheidseconomisch perspectief kan samenvattend

geconcludeerd worden dat het zelfmanagementprogramma minimaal even efficiënt is als de reguliere astmazorg.

Hoofdstuk 8: richtlijn versus realiteit

In 2000 werd in de British Medical Journal een studie gepubliceerd naar de opvattingen van Britse astmapatiënten, huisartsen en praktijkverpleegkundigen over zelfmanagement. Hoewel zelfmanagement in Britse behandelrichtlijnen nadrukkelijk wordt geadviseerd, blijkt de bereidheid en interesse om zelfmanagement toe te passen opvallend laag. Hoofdstuk 8 is een redactioneel commentaar dat in het kader van deze bevindingen is geschreven. In dit commentaar wordt uiteengezet dat brede acceptatie van zelfmanagement een belangrijke voorwaarde is voor het daadwerkelijk toepassen. Essentieel voor deze brede acceptatie is overeenstemming tussen patiënten en hulpverleners over de doelen van astmabehandeling en de mogelijkheden van alle betrokkenen. Belangen van hulpverleners kunnen gemakkelijk haaks op die van de patiënt komen te staan. Erkenning en acceptatie door hulpverleners van de eigen keuzes van patiënten en erkenning en acceptatie door patiënten van de medische aspecten zijn nodig om tot een gemeenschappelijke 'agenda' te komen. Zelfmanagement is er op gericht de autonomie en de inbreng van de patiënt te versterken en zo de patiënt meer verantwoordelijkheid voor de omgang met zijn ziekte te geven. Juist door deze typische eigenschappen is zelfmanagement een zeer geschikte behandelstrategie om op basis van een meer gelijkwaardige samenwerking de (schijnbare) kloof tussen het medische en het persoonlijke perspectief te overbruggen.

Hoofdstuk 9: de meerwaarde van zelfmanagement

Dit proefschrift is het resultaat van een onderzoeksproject dat in 1995 gestart is. Gedurende dit project zijn zowel eigen inzichten als internationale inzichten gegroeid en veranderd. In hoofdstuk 9 wordt een overzicht gegeven van de kennis en inzichten ruim 5 jaar na de start van het onderzoeksproject. Uit een overzicht van een aantal belangrijke studies naar de effecten van zelfmanagement kan geconcludeerd worden dat zelfmanagement winst oplevert voor zowel patiënten als hulpverleners. Zelfmanagement leidt tot een reductie van ziekenhuisopnames en

Eerste Hulp bezoek. Ook werkverzuim als gevolg van astma neemt af en er zijn zelfs aanwijzingen dat het hebben van een zelfbehandelplan het risico op sterfte door astma reduceert. Vanuit maatschappelijk perspectief leidt zelfmanagement tot een verlaging van astmagerelateerde kosten. Deze bevindingen schetsen een zeer positief beeld over de mogelijkheden van zelfmanagement, maar enige relativering is op zijn plaats. De meeste studies zijn gedaan bij patienten die werden behandeld door de longarts, frequent de Eerste Hulp bezochten of patienten die nog geen goed georganiseerde astmazorg ontvingen. De studies die in huisartspraktijken gedaan zijn tonen aan dat aldaar behandelde astmapatienten in veel gevallen goed tot redelijk onder controle zijn, waardoor er veel minder ruimte voor verbetering is. Daardoor kunnen de beschreven positieve bevindingen vaak niet of niet goed worden bevestigd. Dit laat echter onverlet dat een zelfmanagementprogramma bestaande uit patientgeoriënteerde voorlichting, training van noodzakelijke vaardigheden en een geschreven zelfbehandelplan een efficiënte oplossing kan zijn om de belangen van de patient en de huisarts in een samenhangend programma te verenigen. Zelfmanagement onderscheidt zich hierbij niet zozeer door de inhoud van het programma, maar door de benadering van de patient. Het vraagt een andere houding van de arts ten opzichte van de patient. De arts moet (leren te) accepteren dat patienten vanuit medisch oogpunt niet altijd de meest gewenste keuzes maken. De verantwoordelijkheid van de arts is gelegen in het creëren van de optimale omstandigheden voor zelfstandigheid van de patient. Zelfmanagement dient patienten uit te dagen tot onafhankelijkheid van de arts, tot de bereidheid om zelfbewust en weloverwogen keuzes te maken en tot het exploreren van de eigen mogelijkheden om met astma om te gaan. In dit proces van 'probleemgericht' leren kan de arts als coach optreden. Laagdrempeligheid en de continuïteit van zorg zijn typische kwaliteiten van de huisartsgeneeskunde. Het zijn ook belangrijke randvoorwaarden voor de typisch patientgeoriënteerde samenwerking die zelfmanagement kan zijn. Vanuit dit perspectief is er dan ook zeker een plaats voor zelfmanagement in de huisartspraktijk. Zoals in hoofdstuk 8 staat, is het dan niet zozeer de vraag of zelfmanagement effectiever is dan de gangbare zorg, maar meer of zelfmanagement een methode kan zijn om de belangen van patient en arts op basis van gelijkwaardige samenwerking tot hun recht te laten komen.

Hoofdstuk 10: conclusies en aanbevelingen

De belangrijkste bevindingen van het ZBA-project zijn:

1. Astma zelfmanagement is een verantwoorde methode voor intermitterende behandeling met inhalatiecorticosteroiden.
2. Bij astma zelfmanagement hebben patiënten minder last van hun astma, terwijl het behoud van longfunctie minstens even goed is als bij reguliere astmazorg.
3. Met inbegrip van de indirecte kosten is astma zelfmanagement minstens even efficiënt en mogelijk efficiënter dan reguliere astmazorg.
4. Het gebruik van hulpmiddelen om meer systematisch rekening te houden met de behoeften van patiënten, zorgt voor een betere balans tussen de belangen van patiënt en huisarts en een meer patiëntgeoriënteerde astmazorg.
5. Bij het geven van voorlichting aan astmapatiënten is het van belang dat de patiënt zich meer bewust wordt van mogelijk relevante onderwerpen. Hierin heeft de huisarts een belangrijke taak.
6. Astmapatiënten die in de huisartspraktijk behandeld worden gebruiken vaak lage tot gemiddelde doseringen inhalatiesteroiden. De acceptatiegraad van zelfmanagement in deze categorie patiënten is voldoende hoog om zelfmanagement in de huisartspraktijk te kunnen implementeren.
7. De acceptatiegraad van astmazelfmanagement onder huisartsen is voldoende hoog om zelfmanagement te kunnen implementeren in de huisartspraktijk.
8. Zowel nationaal als internationaal opgedane kennis over de meerwaarde en bruikbaarheid van astma zelfmanagement rechtvaardigen een bredere aanbeveling van zelfmanagement in de NHG richtlijn 'Astma bij volwassenen: behandeling'.

De conclusies uit het ZBA-project gelden met name voor patiënten die door hun huisarts behandeld worden voor mild tot matig persisterend astma. Een eerste stap bij het toepassen van zelfmanagement is hierbij het zo optimaal mogelijk stabiliseren van astma door de huisarts. Toepassing van zelfmanagement vanuit deze basis maakt astma zelfmanagement een efficiënte methode om tot een meer patiëntgeoriënteerde behandeling van astma te komen. Zelfmanagement

onderscheidt zich in positieve zin van de gangbare astmazorg op de patiëntgerelateerde uitkomsten en de economische consequenties hiervan. Verschillen tussen huisartspraktijken qua organisatievorm en grootte zijn niet bepalend voor de toepasbaarheid en effectiviteit van zelfmanagement. De mogelijkheden voor zelfmanagement lijken eerder door de patiënt bepaald te worden. Niet alle patiënten kunnen of willen met zelfmanagement beginnen. Soms zal eerst gepraat moeten worden over de bereidheid om een noodzakelijke onderhoudsbehandeling te starten, soms zal eerst onder begeleiding van de huisarts de mogelijkheid om een ingestelde therapie af te bouwen moeten worden verkend. Het zelfmanagementprogramma dat in het ZBA-project gebruikt is, is gebaseerd op de toenmalige inzichten over zelfmanagement. Daarom is gekozen voor een programma waarin verschillende interventies in een logisch samenhangend geheel worden aangeboden: patiëntenvoorlichting, training van vaardigheden en een geschreven zelfbehandelplan. In hoofdstuk 10 worden een aantal mogelijkheden geschetst om de efficiëntie van dit programma verder te vergroten. De introductie van de praktijkverpleegkundige in de Nederlandse huisartspraktijk biedt een aantal veelbelovende kansen. Maar ook de ontwikkelingen als bijvoorbeeld de samenwerking tussen huisarts en bedrijfsgeneeskundige dienst bieden nieuwe mogelijkheden.

In hoofdstuk 10 worden naar aanleiding van het ZBA-project de volgende aanbevelingen gedaan:

- Op grond van de resultaten van het ZBA-project kan geconcludeerd worden dat het zelfmanagementprogramma dusdanig succesvol is geweest dat toepassing in de Nederlandse huisartspraktijk wordt aanbevolen. Zelfmanagement moet hierbij niet de reguliere astmazorg vervangen. Het is een volwaardig alternatief en een verantwoorde methode als intermitterende behandeling met inhalatiecorticosteroiden wordt overwogen of gewenst is.
- De huidige aanbeveling in de NHG standaard 'Astma bij volwassenen: behandeling' om '....ten minste zelfbehandelingsadviezen (schriftelijk en mondeling) en een piekstroommeter te geven aan volwassenen met ernstig astma, aan diegenen met een wisselend patroon en diegenen die in een

ziekenhuis opgenomen zijn wegens astma' dient te worden uitgebreid naar alle patiënten die lage tot gemiddelde doseringen inhalatiecorticosteroïden (zouden moeten) gebruiken. Dit zijn in het algemeen patiënten met mild tot matig persisterend astma. Deze aanbeveling dient prominenter te zijn dan alleen een vermelding in het notenapparaat.

- Er is verder onderzoek nodig om de vraag te beantwoorden of er meer specifieke patiëntkenmerken zijn die kunnen voorspellen of iemand wel of geen baat heeft bij zelfmanagement.
- Het zelfmanagementprogramma kan wellicht nog verbeterd worden door overbodige of overlappende elementen te verwijderen, zodat alleen de meest effectieve onderdelen overblijven. Ook de eventuele toevoeging van zinvolle onderdelen verdient aandacht.
- Wellicht kan een deel van de gevonden effecten worden toegeschreven aan het deelnemen aan een strak georganiseerd wetenschappelijk experiment. Op termijn kan wellicht de vraag beantwoord worden op welke manier patiënten doorgegaan zijn met zelfmanagement na het onderzoeksproject en of de gevonden effecten zijn gebleven.

Aan het eind van deze samenvatting moge duidelijk zijn dat er nog mogelijkheden en onbeantwoorde vragen zijn, die de efficiëntie van zelfmanagement kunnen vergroten. Desondanks kan nu reeds geconcludeerd worden dat zelfmanagement van astma, gericht op gedeelde verantwoordelijkheid en patiëntgeoriënteerde samenwerking, de efficiëntie van astmazorg doet toenemen. Het zoeken naar antwoorden op de nog openstaande vragen is dan ook geen reden om toepassing van zelfmanagement in de Nederlandse huisartspraktijk uit te stellen, het zal de resultaten alleen maar beter maken.

GP manual for patient education: general instructions and example of first visit (both in Dutch)

Algemene instructies

Tijdens het ZBA-onderzoek ziet u de patiënt op zeven "geplande" consulten (1 t/m 7). Voor elk van deze consulten vindt u een draaiboek in deze map "**Materialen huisarts**". Als u het draaiboek voor het betreffende consult van begin tot eind volgt tijdens het consult, verschaft u de patiënt stapsgewijs de informatie die hij of zij nodig heeft voor het uitvoeren van zelfbehandeling. De *cursief gedrukte tekst* kunt u desgewenst *letterlijk 'voorlezen'*, maar u kunt ook alleen gebruik maken van de in HOOFDLETTERS weergegeven KERNWOORDEN. **Vet gedrukte tekst** geeft de dingen aan die **u zelf moet doen**.

De inhoud van de patiëntenvoorlichting heeft als belangrijkste doelen de ondersteuning van het zelfbehandelingsplan en het motiveren van de patiënt. De opzet is om in eerste instantie beperkte informatie aan te bieden. Als de patiënt aangeeft behoefte te hebben aan meer voorlichting of advies over een specifiek onderwerp (bv. stoppen met roken, sanering), dan is het aan te bevelen om daarvoor extra tijd te reserveren.

Het leren van het gebruik van de dag- en weekrapporten en het zelfbehandelingsplan gebeurt stapsgewijs. De opbouw van de consulten is hier op afgestemd. Het belangrijkste is steeds dat de patiënt zelf gaat oefenen. Trial en error is de beste leerschool voor een gecompliceerd behandelplan. Uw rol hierin is het adviseren en begeleiden van de patiënt bij het ontdekken van alle mogelijkheden en moeilijkheden.

Voorlichtingsconsult 1

Geschatte duur 30 minuten

VOORBEREIDING

0		Materialen	<ul style="list-style-type: none">- Neem uit de map 'Materialen patiënten' het hele plastic mapje van de patiënt.- Haal uit dit mapje:<ul style="list-style-type: none">* De brochure 'Omgaan met astma'* Het 'Voorlichtingsregistratieformulier voor de huisarts'- Pak een piekstroommeter- Pak twee dagboekjes.- Roep de patiënt binnen
---	--	-------------------	--

UITLEG ZELFBEHANDELINGSONDERZOEK

1		Inleiding	<i>Dit consult is bedoeld om u uit te leggen WAT HET zelfbehandelingsONDERZOEK INHOUDT. Tevens zullen we vandaag een BEGIN MAKEN MET u te leren hoe u de zelfbehandeling kunt TOEPASSEN</i>
2		Belang en doel	<i>Dit onderzoek is opgezet door de KATHOLIEKE UNIVERSITEIT NIJMEGEN. Onderzocht wordt of het 'ZO NODIG GEBRUIK' van de ontstekingsremmer PULMICORT net zo goed is, of misschien wel beter, dan CONTINUE BEHANDELING met dat middel</i>
3		Inhoud en duur	<i>Het onderzoek duurt TWEE JAAR. In dit onderzoek gaat u als het ware een deel van mijn werk over nemen. Aan de hand van een DAGRAPPORT gaat u zelf BIJHOUDEN hoe het met uw astma gaat en zondig de behandeling met Pulmicort aanpassen</i>
4		Willen stoppen	<i>Ik vind het als huisarts erg belangrijk dat astmapatiënten zelf hun behandeling op een goede manier kunnen aanpassen. Vandaar dat ik hoop dat u het onderzoek helemaal af zult maken. Mocht u echter toch tussentijds willen stoppen met het onderzoek, dan kan dit altijd. Neem dan wel even met mij contact op</i>
5		Materiaal	<i>Toon het dagboekje aan de patiënt. DIT BOEKJE zult u de komende twee jaar gaan gebruiken. Het is de BASIS VAN HET ONDERZOEK en HELPT U bij de zelfbehandeling. Ik zal u STRAKS MEER over dit boekje vertellen</i>

ALGEMENE VOORLICHTING OVER ASTMA

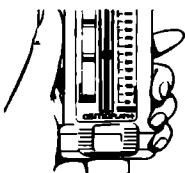
6	Aard en oorzaak van astma	<p>Astma is een LEVENSLANGE ZIEKTE met een WISSELEND BELOOP. Vaak is er een ERFELIJKE AANLEG. Astma wordt GEKENMERKT door VERNAUWING VAN DE LUCHTWEGEN. Deze vernauwing kan de volgende KLACHTEN veroorzaken:</p> <ul style="list-style-type: none"> - kortademigheid (in aanvallen) - piepen, zagen, brommen - hoesten - 'volzuren' - opgeven van slijm
7	Prognose	<p>Astma is NIET TE GENEZEN, maar je kunt wel KLACHTEN BEHANDELEN. Dit heeft een GUNSTIGE INVLOED op het BELOOP van de ziekte.</p>
8	Hyperreactiviteit en allergie allergietest	<p>Astmapatiënten hebben PRIKKELBARE LUCHTWEGEN. Luchtwegen worden geprikkeld door ALGEMENE PRIKKELS (hyperreactiviteit), zoals:</p> <ul style="list-style-type: none"> - (sigarette-) rook - temperatuurswisselingen - infecties - emoties/stress - inspanning <p>en/of door SPECIFIEKE PRIKKELS, zoals:</p> <ul style="list-style-type: none"> - huisstofmijt - huisdieren - stuifmeel <p>Als je gevoelig bent voor dergelijke prikkels ben je ALLERGISCH. Du kan je bepalen met een HUDPRIKTEST, of een BLOEDONDERZOEK (EENMALIG).</p>

9	<p>Mechanisme kortademigheid</p> <p>VERNAUWDE LUCHTWEG</p>	<p>Kortademigheid ontstaat door VERNAUWING VAN DE LUCHTWEGEN ('ademen door een rietje'). Dit ontstaat door VERKRAMPING van de SPIERTJES om de luchtwegen en doordat de SLIMVLIEZEN OPZWELLEN en MEER SLIJM gaan maken. Dit laatste noemen we ONTSTEEKING van de luchtwegen.</p> <p>Gebruik eventueel de illustratie hiernaast om bovenstaande voor de patiënt te verduidelijken.</p>
---	---	--

10	Boekje Astma Fonds	Geef het boekje 'Omgaan met astma' aan de patiënt <i>Wat ik u zojuist verteld heb kunt u THUIS RUSTIG NALEZEN in dit boekje van het Astma Fonds</i>
11	Longfunctieonderzoek	<i>Vernauwing van de luchtwegen kan je meten. Dit is de meting die u al gehad heeft OP HET LONGFUNCTIE LABORATORIUM.</i>
12	Piekstroom en klachten	<i>De longfunctie kunt u op een EENVOUDIGE manier zelf in de gaten houden door THUIS de PIEKSTROOM en uw ASTMAKLACHTEN bij te houden in een DAGBOEK. Dit gaan we de komende TWEE WEKEN DAGELIJKS THUIS OEFENEN</i>

INSTRUCTIE VAARDIGHEDEN

13	Instructie piekstroommeting	<p>Geef de patiënt een piekstroommeter</p> <p><i>Om uw longfunctie goed te kunnen meten is het belangrijk dat u deze piekstroommeter op de GOEDE MANIER gebruikt. Dat gaan we nu OEFENEN</i></p> <ul style="list-style-type: none"> • Zet het mondstuk op de meter (zie tekening) • Schuif de rode wijzer zo dicht mogelijk naar het mondstuk toe • Houd de piekstroommeter vast zoals op de tekening • Ga staan en adem zo diep mogelijk in • Plaats het mondstuk van de meter tussen lippen en tanden • Blaas kort en zo hard mogelijk in het mondstuk • Lees de stand van de wijzer af (zie tekening) • Herhaal de meting nog 2 keer en schrijf de hoogste waarde op
----	-----------------------------	---



14 Invullen dagrapport

Piekstroom- waarde	Uw beste waarde tot nu toe	Ochtend	Avond
Meet uw piekstroom- waarde iedere dag. Meet 's ochtends vlak voor u uw u-inhaler gebruikt. Meet 's avonds, 3 keer en schrijf de beste meting van de drie op. Het is het gemiddelde van de drie metingen. Eens op twee staat hoe u uw piekstroommeter gebruikt.	Is uw piekstroom- waarde boven de 520 vul dan hiermee uw waarde in		
	Is uw piekstroom- waarde tussen de 390 en 520 vul dan hiermee uw waarde in		
	Is uw piekstroom- waarde tussen de 260 en 390 vul dan hiermee uw waarde in		
	Is uw piekstroom- waarde onder de 260 vul dan hiermee uw waarde in		

U heeft nu met de patiënt geoefend.

Schrijf op het DAGrapport de hoogste gemeten piekstroom op in het grijze vakje 'Uw beste waarde tot nu toe'

BEPAAI de 80, 60 en 40% grenswaarden

Vul op het DAGrapport in:

- bij groen: de 80% waarde,
- bij geel: eerst de 60 en dan de 80% waarde,
- bij rood: eerst de 40 en dan de 60% waarde,
- bij lila: de 40% waarde.

Zet op de piekstroommeter:

- het groen/gele schuifje op de 80% waarde
- het geel/rode schuifje op de 60% waarde
- het rood/lila schuifje op de 40% waarde

15 Uitleg aan de patiënt

Geef nu het ingevulde boekje aan de patiënt.

Ik heb nu de HOOGSTE PIEKSTROOMWAARDE die u zojuist geblazen heeft hier op uw dagrapport geschreven (WIJS DE HOOGSTE WAARDE AAN). Deze waarde noemen we de PERSOONLIJKE BESTE WAARDE. Daarna heb ik berekend welke piekstroomwaarden in uw geval horen bij de kleuren groen, geel, rood en lila. Deze KLEUREN GEVEN AAN hoe u straks uw ASTMA HET BESTE ZELF kunt BEHANDELEN. Hierover vertel ik u in HET VOLGENDE CONSULT meer.

Op uw PIEKSTROOMMETER kunt u aan de GEKLEURDE PIJLTJES, die ik voor u heb ingesteld, de GROENE, GELE, RODE EN LILA ZONES herkennen.

16 Invulinstructie voor de patiënt

Ik zou nu graag zien dat u THUIS 'S MORGENS EN 'S AVONDS uw piekstroom gaat METEN EN OPSCHRIJVEN in uw

			<p>dagrapport. Meet uw piekstroom steeds VOORDAT u uw ASTMAMEDICIJNEN INHALEERT!</p> <p>Meet net als zojuist, DRIEMAAL PER KEER en noteer de HOOGSTE WAARDE van deze drie metingen. Noteer deze waarde dan wel bij het GOEDE MOMENT van de dag en in de GOEDE GEKLEURDE BALK. We zullen dat nu eens samen oefenen</p>
17	Oefenen met de patiënt	Piekstroom	<p>Stel, uw piekstroomwaarde van deze ochtend was Noem een piekstroomwaarde uit de gele zone (tussen de 60 en 80%)</p> <p>Kruis u de DATUM VAN VANDAAG én deze PIEKSTROOM-WAARDE nu eens voor mij in het boekje schrijven</p> <p>Controleer of:</p> <ul style="list-style-type: none"> - de datum van vandaag boven aan bij de juiste dag van de week en op de juiste wijze (dag-maand-jaar) is ingevuld, - de piekstroom in de kolom met de juiste dag van de week (vandaag) staat, - de piekstroom in de kolom 'Ochtend' staat, - de piekstroom in de gele zone staat.
18	<p>Klachten</p>		<p>Naast het bijhouden van de piekstroom is ook het BIJHOUDEN VAN UW KLACHTEN van belang, om te zien hoe het met uw astma gaat. Kruis ELKE AVOND hier aan of u de afgelopen dag last heeft gehad van één of meer van de genoemde klachten</p> <p>Wijls in het dagboek het onderdeel 'Klachten' aan met de groene, gele, rode en lilie zone.</p> <p>(Schrijf de naam van de door de patiënt gebruikte kortwerkende luchtwegverwijder op in het vakje voor de rode zone)</p> <p>Laat de patiënt aankruisen hoe deze zich op dit moment voelt</p> <p>Controleer of het kruisje/de kruisjes in de kolom met de juiste dag van de week (vandaag) staat/staan.</p>
19	<p>Astmamedicijnen</p>	Zondag	<p>Ook is het de bedoeling dat u hier opschrijft hoeveel astmamedicijnen u dagelijks gebruikt</p> <p>Wijls in het dagboek het onderdeel 'Astmamedicijnen' aan en noteer daar de naam van de gebruikte luchtwegverwijder(s).</p> <p>Laat de patiënt de gebruikte medicatie van vandaag invullen.</p> <p>Controleer</p> <ul style="list-style-type: none"> - of de gegevens in de kolom met de juiste dag van de week (vandaag) staan, - of het 'aantal keer per dag' in het juiste hokje is ingevuld, - of het 'aantal puffes per keer' in het juiste hokje is ingevuld.

20	Symptomen		Zondag
	Geef in de vakjes hiernaast aan hoeveel last u de afgelopen dag van deze klachten gehad heeft, vul bij elke klacht een van de tekens in die helemaal rechts staan	Benaauwdheid	3 357
		Piepende ademhaling	0 360
		Hoesten	3 363

Voor het onderzoek willen we ook graag weten hoeveel last u heeft van benauwdheid, piepende ademhaling en hoesten. Geef dit IEDERE DAG met behulp van de 'Klachtenscore' aan.

Wijns in het dagboek het onderdeel 'Symptomen' aan en wijs helemaal aan de rechterzijde aan waar de 'Klachtenscore' staat.

Laat de patiënt alle drie de symptomen voor vandaag scoren.

Controleer:

- of de scores in de kolom met de juiste dag van de week (vandaag) staan,
- of bij elk symptoom een score is ingevuld.

21	Invullen basisgegevens	
	Patiëntnummer	12345
	Geboortedatum <small>dag maand jaar</small>	23-01-67

Vul nu zelf op het dagrapport in:

- patiëntnummer
- geboortedatum (dag-maand-jaar)

Laat de patiënt de gegevens op de voorflap invullen.

AFRONDING CONSULT

22	Nieuwe afspraak
----	------------------------

- Geef de patiënt een tasje van het Astma Fonds om alle materialen in te bewaren.
- Laat de patiënt bij de assistente een NIEUWE AFSpraak van 20 minuten - DUBBEL CONSULT- plannen voor over TWEE WEKEN. Wijs de patiënt er op dat deze zich 10 minuten vóór dit consult bij de assistente meldt om alvast een formulier in te vullen. ('Astma voorlichtingsregistratie-formulier voor de patiënt')
- Wijs erop, dat de patiënt bij het volgende consult opneuw de dagboekjes, piekstroommeter, Turbuhaler en informatiebrochure meeneemt
De patiënt kan nu via de assistente naar huis.

CONSULTREGISTRATIE

23	Geboortedatum: 23 01 67																													
	<table border="1"> <tr> <td colspan="5">Consulten:</td> </tr> <tr> <td></td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>Datum consult:</td> <td>3/3</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td>36</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td>X</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	Consulten:						1	2	3	4	5	Datum consult:	3/3						36						X				
Consulten:																														
	1	2	3	4	5																									
Datum consult:	3/3																													
	36																													
	X																													

- Vul het 'Astma voorlichtingsregistratieformulier voor de huisarts' in. Kruis daarvoor de voorlichtingsitems, die in dit consult aan bod zijn geweest, aan in de kolom van consult 1. Vergeet niet onderaan de DUUR VAN HET CONSULT te noteren.
- Scheur hierna de achterste doorslag van dit formulier af en stuur ALLEEN DEZE DOORSLAG met een portvrije retourenvelop naar Nijmegen.
- Stop de rest van dit formulier terug in het plastic mapje van de patiënt, in de map 'Materialen patiënten'.

HET EERSTE CONSULT IS NU KLAAR

Dankwoord

Dit proefschrift gaat over zelfmanagement, een kwaliteit die ook voor een promovendus geen overbodige luxe is gebleken. Toch heb ik dit proefschrift niet alleen gemaakt. Het is voor mij dan ook vanzelfsprekend dat een dankwoord aan iedereen die bij het ZBA project betrokken is geweest, integraal onderdeel van dit proefschrift moet zijn.

Voor mij begon het ZBA project in het najaar van 1995. Het project heette toen 'Zelfbehandeling van astma voor patiënten met inhalatiecorticosteroiden in de huisartspraktijk'. Een titel die voor een kortademige astmapatiënt natuurlijk niet uit te spreken is en waarvoor dan ook al snel het acroniem ZBA werd bedacht. Bij het organiseren van het ZBA project zijn veel mensen betrokken geweest. In de beginfase van het project zijn er twee mensen die ik speciaal wil bedanken. Dit zijn Lud Beijers en Ivo Smeele. Het opzetten van de logistiek van dit onderzoeksproject was voor mij pionieren. Gelukkig was er altijd de inbreng en kritische toets van Lud, waardoor de hele logistiek tot in detail kon worden uitgewerkt. Lud, jouw inbreng in deze fase van het project heeft er zeker toe geleid dat ZBA ook in logistieke zin een succes is geworden. Ik kijk dan ook met plezier op onze samenwerking terug en verheug me op eventuele nieuwe projecten, waarin we kunnen samenwerken. Ook Ivo wil ik in de context van het opzetten van het project speciaal bedanken. Jij was altijd de pragmatische toets die er voor waakte dat het zelfmanagement programma voor huisartsen en patiënten waardevol en uitvoerbaar bleef. Daarnaast bleef je in de verdere loop van het project een waardevolle toetssteen voor mijn ideeën. Maar vooral onze gesprekken over de balans tussen werk en gezin heb ik als een zeer waardevolle steun gevoeld bij het maken van mijn eigen keuzes.

Toen het project geleidelijk aan zijn vorm begon te krijgen, bleken er bergen werk verzet te moeten worden. De binnenkomst van Tjard (toen nog als onderzoeksassistent) bleek een gouden greep. Tjard, je bleek niet alleen een zeer goede steun bij al het werk van ontwerpen, drukken, sorteren en verspreiden van boekjes en formulieren. Je was daarnaast ook een gezellige collega om mee samen te werken. Dit is altijd zo gebleven, maar de manier waarop je in de loop van de

afgelopen jaren ook inhoudelijk bij het project betrokken bent geraakt, was voor mij van onschatbare waarde. Naast een prachtige kosten-effectiviteits analyse (of KEA, voor de kortademigen) ben je voor mij altijd degene die me methodologisch op het rechte en objectieve pad wist te houden. Het was en is de basis voor een vruchtbare samenwerking.

De basis van het ZBA-project was natuurlijk het eigenlijke experiment. De hoofdrolspelers die ik zeker niet over wil slaan in dit dankwoord zijn dan ook de deelnemende patiënten en hun huisartsen. Met zeer veel toewijding en geduld werden vele vragenlijsten bijgehouden, waarvan de 18.388 dag- en weekrapporten en de 859 consultformulieren nog maar het topje van de spreekwoordelijke ijsberg vormen. Zonder de wijze waarop de huisartsen invulling hebben gegeven aan hun astmazorg en de loyaliteit waarmee patiënten vragenlijsten en dagboekjes hebben bijgehouden, was dit onderzoek nooit gelukt. Er zijn een paar mensen en praktijken die ik in deze context speciaal wil bedanken. Dit zijn allereerst de longfunctieassistentes die alle metingen hebben gedaan: Lilian, Vicky, Maria en Lisette. Bedankt voor de altijd correcte en toch zeer persoonlijke bejegening van de patiënten, jullie voortvarendheid bij het plannen van alle afspraken en de hoge kwaliteit van de verzamelde data. Er is ook een praktijk die ik speciaal wil bedanken, het 'Gezondheidscentrum Stratum'. Als 'pilotpraktijk' waren jullie vanaf het prille begin betrokken bij het testen van alle procedures en protocollen. Dit vond ik zeer waardevol. Naast de altijd gastvrije ontvangst met soms een vleugje Koot en Bie zijn jullie daardoor voor mij altijd een speciale praktijk gebleven.

Ook in Nijmegen is het project door vele mensen ondersteund. Twanny en Lea, jullie hebben vele klussen voor het project gedaan. Zo zijn er bijvoorbeeld 911 Turbuhalers geteld en van alle formulieren die deels door Harry en deels door jullie zijn ingevoerd, ben ik de tel kwijt geraakt. In deze context wil ik ook Reinier bedanken voor zijn bijdrage. Het organiseren en analyseren van al het materiaal vond ik erg leuk en interessant. Maar als het moeilijk werd, dan mocht jij het overnemen. De meest ingewikkelde analyses waren dan altijd in een oogwenk weer

gedaan en na jouw uitleg kon ik ze nog interpreteren ook. Je hebt dan ook een onmisbare bijdrage geleverd aan het analyseren en interpreteren van alle gegevens.

Binnen het project hebben diverse studenten en assistenten meegelopen. Marielle, Marie-José, Manon, Elke, Edith en Zineta, in jullie stages hebben jullie deelvragen van het project beantwoord, waarvoor de gegevens vaak met veel monnikenwerk moesten worden uitgezocht. Dat jullie dit telkens tot een goed eind brachten is een compliment waard. Ik hoop dat jullie veel binnen het project geleerd hebben en net zoveel plezier van de stages hebben gehad als ikzelf. Op deze plaats wil ik ook Marjolein, Chantal en Miranda bedanken. Dankzij jullie assistentie hebben we in een korte tijd veel bruikbare gegevens beschikbaar gekregen.

De inhoudelijke ondersteuning van het project door Onno van Schayck en Richard Grol bleek een goede combinatie. Onno, jij liet me zeer zelfstandig werken binnen het project. Dat gaf mij de kans om me het project in een vroege fase echt eigen te maken. Ik kon echter altijd voor overleg bij je terecht en je vertrouwen in de goede afloop van het project was een steun in de rug. Na je vertrek naar Maastricht vond ik het een stuk lastiger om de inhoudelijke voortgang van het project te blijven afstemmen. Dank zij de moderne communicatiemiddelen en enkele gezamenlijke congressen bleek het echter opgelost te kunnen worden en ik ben blij dat je tot het eind van het project inhoudelijk betrokken bent gebleven. Richard, ook jou wil ik hier als promotor speciaal bedanken. Je had vaak een rol die ik in eerste instantie best lastig vond. Als ik dingen even snel wilde regelen of dacht alles netjes opgeschreven te hebben, dan trok jij vaak aan de rem. Dit was echter nooit zonder reden. Je inhoudelijke commentaren en correcties sneden hout en ik merk dat ik daardoor kritischer naar mijn eigen schrijfstijl ben gaan kijken. Je hebt daarmee zowel aan mijn eigen groei, als aan de kwaliteit van het project een belangrijke bijdrage geleverd.

Naast beide promotores kende het ZBA project ook een begeleidingscommissie bestaande uit: Chris van Weel, Cees van Herwaarden, Johan Molema, Hans Folgering, Gijs Bleijenberg, Henk van den Hoogen, Ivo Smeele, Guido van den Boom en Joost den Otter. Vele plannen en versies van mijn protocol en publicatieplan

hebben jullie gewillig aanhoord en hier is dan het uiteindelijke product! Dank voor jullie bijdrage en gewaardeerde expertise. Een paar leden van de begeleidingscommissie wil ik nog speciaal bedanken, namelijk Chris van Weel en Guido van den Boom. Jullie wisten beiden in een cruciale fase van het project met zeer verfrissende inzichten en ideeën mijn output weer op stoom te krijgen. Guido, jouw analytische manier van kijken heeft mij weer een heel andere manier van schrijven geleerd. Je was een goede 'sparringpartner' om mijn gedachten helder te krijgen en scherp in de artikelen te formuleren. Bedankt daarvoor.

Iemand die ik aan het eind van dit proefschrift ook speciaal wil bedanken is André Knottnerus. André, je bent niet bij dit onderzoek betrokken geweest, maar je stond wel aan de wieg van mijn wetenschappelijke carrière. Door de manier waarop jij mij kennis hebt laten maken met wetenschappelijk onderzoek in de huisartsgeneeskunde, ben ik er voor altijd aan verknocht geraakt. Ik vond en vind het zeer bijzonder dat je door alle jaren heen ook precies bleef weten waar ik mee bezig was en heb je welgemeende en persoonlijke belangstelling altijd zeer gewaardeerd.

Het laatste deel van mijn dankwoord heb ik voor een paar zeer speciale mensen gereserveerd. Om te beginnen zijn dit mijn kinderen: Maarten, Wouter, Vera en Anne. Het doen van een promotie onderzoek heeft mij niet alleen dit proefschrift opgeleverd. Jullie zijn er ook bijgekomen. Dankzij jullie komst heeft de totstandkoming van dit proefschrift wat langer geduurd. Het is er alleen maar beter van geworden. Jullie hartverwarmende afleiding zorgde ervoor dat ik mijn vaderrol niet uit het oog hoefde te verliezen. En dat was maar heel af en toe tegen wil en dank!

Ook mijn ouders en schoonouders verdienen een speciale plaats in dit dankwoord. Jullie ondersteuning, zeker gedurende de laatste drie jaar is zeer bijzonder geweest. Zonder deze steun had ik het nooit gered en dit proefschrift is daarmee ook een beetje jullie proefschrift. Ik benoem jullie daarom tot doctor in de mantelzorg! Ook Tante Riet verdient een speciaal woord van dank. De energieke wijze waarop jij er bent voor onze kinderen en de zekerheid dat de kinderen bij jou in goede handen zijn, is een grote steun.

Desirée, de laatste tijd vroegen we ons wel eens gekscherend af waarvoor ik je zou gaan bedanken. We waren het er over eens dat het niet hoefde te gaan over de opvang van de kinderen of het geduldig tolereren van afwezigheid. En toch wil ik je hier speciaal bedanken. Ik wil je bedanken omdat je er was en voor de manier waarop we samen dit punt hebben bereikt. Zeker met de komst van 'de drieling' werden onze toekomstplannen behoorlijk op de proef gesteld. Samen moesten en moeten we opnieuw onze weg bepalen en er voor knokken. Deze promotie is voor mij niet alleen de bekroning van de 'wetenschappelijke proeve van bekwaamheid'. Het is ook de bevestiging dat we samen veel kunnen bereiken. 'Love lifts us up where we belong'.

Curriculum vitae

Bart Thoonen werd geboren op 29 augustus 1965 te Oss. In 1982 behaalde hij het Atheneum-B diploma aan het Titus Brandsma Lyceum te Oss. Daarna studeerde hij in Maastricht geneeskunde, alwaar hij in 1990 zijn basisartsexamen behaalde. Ook de huisartsopleiding voltooide hij in 1994 aan de Universiteit van Maastricht.

Sindsdien is hij werkzaam geweest als huisarts in Blerick, Zevenaar en Arnhem. De eerste schreden op wetenschappelijk gebied werden gezet tijdens een keuze co-assistentenschap. Sindsdien is hij naast de praktijkwerkzaamheden altijd in meer of mindere mate wetenschappelijk actief geweest, hetgeen geresulteerd heeft in nationale en internationale publicaties. Naast wetenschappelijk onderzoeker is hij sinds enkele jaren ook als docent betrokken bij de opleiding van geneeskundestudenten.

Bart is getrouwd met Desirée. Samen hebben ze 4 kinderen: Maarten, Wouter, Vera en Anne.

Publicaties

Thoonen BPA, Knottnerus JA

Huidige en toekomstige prevalentie van gewrichtsaandoeningen en osteoporose.

Huisarts en Wetenschap; 1991; 43: 369-73

Thoonen BPA, Knottnerus JA, Höppener P

Chronic airway disease in general practice. Prevalence and future development of the number of patients.

Huisarts en wetenschap 1993; 36 (supp): 36-41

Vleuten C van der, Wijnen W

Problem based learning. Perspectives from the Maastricht experience

Thesis 1990

Mede-auteur van het hoofdstuk: Problem based learning from a students perspective

Thoonen BPA, Schayck CP van.

Omgaan met astma: astmamanagement in de praktijk.

Tijdschr. v. Huisartsgeneeskunde 1997;14(9):268-73

Thoonen BPA, Jones KP, Rooij HA van, et al.

Self treatment of asthma: possibilities and perspectives from the practitioner's point of view. Family Practice; 1999: 2: 117-22

BPA Thoonen.

Zelfbehandeling in de huisartspraktijk.

Caravisie; 1999; 1(2): 7-9

BPA Thoonen, CP van Schayck, C van Weel, ML Levy, R Spelman, D Price, D Ryan, D Bellamy, P van Grunsven, S Cloosterman, G van den Boom, W Gorgels, H Schönberger

Present and future management of asthma and COPD: proceedings from WONCA 1998.

Family Practice; 1999: 3: 312-15

M. Schlösser, V. Colland, B. Thoonen

Behandelingsstrategieën bij astma

Hoofdstuk 11: Zelf-management bij volwassen astmapatienten

Cure en Care, 1999

Weel C van, Thoonen BPA

Book review: ABC of allergies. SR Durham

Family Practice; 1999: 5: 548-549

Thoonen BPA, Weel C van

Self management in asthma care. Professionals must rethink their role if they are to guide patients successfully

BMJ: 2000: 321: 1482-83

BMJ-USA:2001;1;12-3 (Dubbelpublicatie)

Thoonen BPA, Rooijackers JM

COPD op het spoor

COPD in perspectief: integrale zorg als uitdaging voor de eerste lijn:2001;1:5-14

Thoonen B, Schermer T, van den Boom G, van Schayck CP

Asthma education tailored to individual patient needs can optimise partnerships in asthma self management.

Bart PA Thoonen, Tjard RJ Schermer, Margreet Jansen, Ivo Smeele, Annelies JE Jacobs, Richard Grol, Onno CP van Schayck

Patient Education and Counseling 2002;47:355-60

Bart PA Thoonen, Tjard RJ Schermer, Reinier P Akkermans, Joost J den Otter, Richard Grol, Onno CP van Schayck

Willingness of patients to perform self management of asthma and the role of inhaled steroids

Scan J Prim Health Care 2002;20:60-4.

Thoonen BPA, Weel C van

Role of family physicians in implementing asthma self management programs

Dis Manage Health Outcomes 2002;10:141-6

Stellingen behorende bij het proefschrift

**Self management of asthma
in
General Practice**

BPA Thoonen

Nijmegen, 16 oktober 2002

1. Bij zelfmanagement van astma hebben patiënten minder last van hun astma, terwijl het behoud van longfunctie gelijkwaardig is aan de reguliere astmazorg (dit proefschrift).
2. Met inbegrip van de indirecte kosten is zelfmanagement van astma minstens even efficiënt en mogelijk efficiënter dan reguliere astmazorg (dit proefschrift).
3. Het gebruik van hulpmiddelen om meer systematisch rekening te houden met de behoeften van patiënten, zorgt voor een betere balans tussen de belangen van patiënt en huisarts en een meer patiëntgeoriënteerde astmazorg (dit proefschrift).
4. Bij het geven van voorlichting aan astmapatiënten is het van belang dat de patiënt zich meer bewust wordt van mogelijk relevante onderwerpen. Hierin heeft de huisarts een belangrijke taak (dit proefschrift).
5. Astmapatiënten die in de huisartspraktijk behandeld worden, gebruiken vaak lage tot gemiddelde doseringen inhalatiesteroiden. De acceptatiegraad van zelfmanagement in deze categorie patiënten is voldoende hoog om zelfmanagement in de huisartspraktijk te kunnen implementeren (dit proefschrift).
6. De acceptatiegraad van zelfmanagement van astma onder huisartsen is voldoende hoog om zelfmanagement te kunnen implementeren in de huisartspraktijk (dit proefschrift).
7. Op grond van de resultaten van het ZBA-project kan geconcludeerd worden dat het zelfmanagementprogramma dusdanig succesvol is geweest dat toepassing in de Nederlandse huisartspraktijk wordt aanbevolen. Zelfmanagement moet hierbij niet de reguliere astmazorg vervangen. Het is een volwaardig alternatief en een verantwoorde methode als intermitterende behandeling met inhalatiecorticosteroiden wordt overwogen of gewenst is (dit proefschrift).

8. De huidige aanbeveling in de NHG standaard 'Astma bij volwassenen: behandeling' om ' .ten minste zelfbehandelingsadviezen (schriftelijk en mondeling) en een piekstroommeter te geven aan volwassenen met ernstig astma, aan diegenen met een wisselend patroon en diegenen die in een ziekenhuis opgenomen zijn wegens astma' dient te worden uitgebreid naar alle patiënten met mild tot matig persisterend astma. Deze aanbeveling dient prominenter te zijn dan alleen een vermelding in het notenapparaat (dit proefschrift).
9. Roken is een verslavingsziekte.
10. Doctor – patient consultations are all too often driven by the health professional and with excellent medications available it is not surprising that consultations tend to be prescription orientated (Dr M Partridge, UK National Asthma Campaign, 2000).
11. A long time ago in a galaxy far, far away ..
12. If it's just us, that would be an awful waste of space.
13. God heeft de wereld rond gemaakt, zodat we niet te ver vooruit kunnen kijken (Isak Denissen, Deens schrijver).
14. Het zijn niet de godsdiensten zelf die aanzetten tot haat en intolerantie, maar de mensen die ze belijden.

Bart Thoonen

